Health literacy and diabetes management in South Asians in the UK: a mixed methods study

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Abstract

This thesis aimed to explore the health literacy needs of South Asians, in particular reference to diabetes management.

This thesis consists of two studies: 1) a survey that examines health literacy levels and 2) study two Photovoice that explore cultural perspective in daily management of diabetes and health literacy needs. In study 1 (N=350), completed a face to face survey using standardised health literacy and diabetes measures. Findings indicated the majority of participants have limited functional health literacy (61%). Findings also suggest that people with certain characteristics, such as old age, females, low socioeconomic status, and people with limited or no formal education, are at a higher risk of inadequate health literacy.

In the study 2, eleven of the participants from study 1 were recruited for Photovoice project and thematic analysis of participant's accounts and images indicated three main themes. 1)*Illustration of self-management of diabetes in day-to day life,* relating to personal lifestyle, capacities and skills to manage different aspects of diabetes in their daily life; 2)*NHS access and utility,* concerning the use of health care services in the management of diabetes. 3) *Quality of life,* connected with the impact of diabetes on quality of life. It has been demonstrated from study two that, despite the limited functional health literacy, participants are able to manage their diabetes and use social support in their families, the distributed resources and health literacy skills of their family members to overcome their personal limited functional capacities.

The consideration of health literacy within a particular community's cultural perspective can have the potential to maximise the assets of that community. In increasing such a level of awareness and contributing towards the evidence of health literacy as an asset approach,

made it possible to use the distributed resources of the social networks and can be one strategy to improve health literacy that can reduce the health disparities in the ethnic communities.

Key words: Health literacy, South Asian, diabetes, mixed methods

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List of Abbreviations

IOM	Institute of Medicine
USA	United States of America
UK	United Kingdom
WHO	World Health Organisation
NHS	National Health Service
PV	Photovoice
BME	Black and Minority Ethnicity
DoH	Department of Health
ESRF	End stage renal failure
NICE	The National Institute for Health and Care Excellence
BMI	Body Mass Index
GP	General Practitioner
NSF	National Service Framework
DESMOND	Diabetes Education and Self-management for Ongoing and Newly Diagnosed
DAFNE	Dose Adjustment for Normal Eating
TA	Thematic analysis

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Alhamdulila.

Preface: a personal introduction

I began my PhD journey with some self-reflexivity and located myself in relation to the research topic. This is very important as it shaped my approach towards topic under study and helped in various stages of this research process.

I was born in a South Asian country and migrated to the UK as an international student in 2011. I left Pakistan as a graduate and continued post-graduate studies after coming to the UK. Panjabi is my first language while in the educational setting I was more used to speaking Urdu. English was a medium of instruction at University level. It was compulsory to have written exams in English while I was not used to speaking English very often. This background information is important because I believe that it helped to shape and influence the research process particularly in recruitment and to encounter the participants. The negotiation of boundaries between me as a researcher and the participants were particularly important in relation to our ethnic status and language. As a member of the South Asian community, it was important to ignore the previous knowledge and experiences and have a reflexive process to increase the receptivity of new information shared by the participants that is called bracketing (Scott et al., 2008).

Apart from these personal biographies, my academic training was also important in influencing how I have approached the research topic and used a methodological approach. I had conducted quantitative research as part of my Masters in Behavioural Sciences at a Pakistani university while in the UK part of the postgraduate study I had explored the experiences of people with mental health issues in a qualitative research project. Both research projects provided an opportunity to explore quantitative and quantitative research methodologies. Further advanced qualitative and quantitative research methods were part

of the MSc in Clinical Psychological Research also enhanced my understanding to apply these approaches in my PhD research study.

During the recruitemnt process, I made contact with the participants through different sources, by visiting the religious places of Muslims and Sikh community, social gatherings and any potential gathering of the community to take benefit in recruiting the participants. During the initial visits to the religious places, I spent some time building rapport and did not start a collection of data upon my first visit. During the initial encounters with the participants, they spent time asking about where I was originally from. Which part of the country was I from? It is interesting that being South Asian helped me to encourage and motivate the participants to be part of the research process. It also kept in mind to have an acceptable outer image and try to dress in a South Asian dress according to the demand of the social/religious setting where I was intended to visit that makes it easy to integrate with the people. Visiting one place also opened up few other potential venues to recruit the participants. In some cases, participants with diabetes also further referred to few more people who also had diabetes. In my opinion having same ethnic status, similar language and understanding of the cultural norms and values were some of the potential reasons of getting more responses from the South Asian community in this research.

Further, entering a new social, cultural environment, I wanted to utilise participatory research to intentionally interrogate my own South Asian identity within the UK. I realised this identity was directly linked to how I helped my research participants to develop and critically reflect on their own identities. Therefore, I began using Photovoice as both a self-study methodology and as a participatory research methodology for my research. In doing so, we are as a learning community will be able to recognise and name

our experiences and needs to make changes needed to help improve health literacy and better health.

Although it is pre-requisite of the validity of the research process that the researcher detached him/herself from the research processes. During this research when participants reflected back to me or conferred their thoughts that made it difficult to have total detachment due to the nature of the topic under study. As some of the shared thoughts have a direct link with me and with my identity of living as an ethnic minority person in the UK.

Much of the research needed within this cultural context, requires me to have distance from my personal experiences, an individual with the same ethnic status like participants. To be more receptive to understand the thoughts and personal experiences shared by the participants that may be different from my personal thoughts. However, like many of my participants before starting to study health literacy. I do not consider myself as a health literate individual. Despite studying in higher education, I was not used to taking intentional efforts to utilise health information or having healthy behaviours and lifestyle. That suggests understanding the notion that education can be ones determinant to health literacy but not the only one. After becoming familiar with the concept of health literacy and its associated health outcomes, all lead to explore further the health literacy that has the potential for positive health outcomes for people with a chronic medical condition such as diabetes.

Specifically how they were managing their condition and what were their health literacy needs in reference to diabetes management. The Photovoice method used in study two was a suitable approach in this regard that it is participatory in nature and it has facilitated participants to reflect on their needs and how these can be met. As study one in

this thesis does demonstrate the health literacy and specifically functional health literacy was a concern in this community.

Finally, over the four years period of conducting this research, I have frequent discussions with family and friends about the use of health information and services of the NHS being an ethnic minority in the UK.

All these opportunities and discussions apart from the research findings thus suggest that health literacy is fundamental to maintain and promote good health and particular area to explore with the groups that may have a risk of low health literacy. It can be considered an important area to explore further to make specific interventions to improve health literacy at the individual level and at the population level to sustain the health benefits associated with improved health literacy of people.

1   Introduction

This thesis revolves around the idea that health literacy is fundamental to improve the health of people. The aims of this introductory chapter are threefold. Firstly, this chapter will illustrate the importance of this research by considering different aspects and placing them in its wider research context. Secondly, the theoretical framework of health literacy that underpins this research will be described. Finally, the structure and overview of this thesis are presented.

1.1   Background

The concept of health literacy is evolving, and there is still no consensus on the definition of health literacy among researchers working in this field. Over the past three decades, many definitions have emerged that show the evolving nature of health literacy as a construct (discussed in chapter 2) that moves beyond individual characteristics to the health care system and wider social competencies and resources. There is considerable research evidence that suggests the association between health literacy and health outcomes (Bains & Egede, 2010; Brega et al., 2012; Mancuso, 2010; McCleary-Jones, 2011; Powell et al., 2007; Gazmararian et al., 2003; Dewalt al., 2007; William et al.,1998; Kim et al., 2004).

The concept of health literacy has gained more importance with the changing demands and complexities of the healthcare systems in the developed countries. Historically, western healthcare systems are built on the acute, episodic model of care in which health care professionals were considered the main source of treatment and patients were a passive recipient of care (Nolte & McKee, 2008). The 21st century has promoted e-

technology, more sophisticated medication, and better treatment options; however, there was less effort made to ensure that all individuals can take advantage of the different sources of health care information of the technological and clinical advancements (Barrett & Puryear, 2006). In this changed modern healthcare context individuals are being pushed to assume responsibility and ownership of their health conditions and are being overwhelmed with issues of personal medical responsibility, accountability and self-management of chronic conditions. The changes in the healthcare settings and provision of health care information and services through the internet, media, and printed material enable some of the individuals to take advantage of the plethora of the information to maintain health. On the other hand, a lot of people may take less benefit of the information provided (Barrett & Puryera, 2006). This is where it is important to consider improving health literacy to make health information and services accessible to everybody and to improve health as a fundamental right for each individual (WHO, 2015).

It is interesting to look into different cultural settings and look at the challenges of taking responsibility in the context of particular chronic disease and community. How health literacy can empower individuals to take responsibility for their health. People living with chronic conditions faced a wide range of adaptive tasks and required to take responsibility of self-management of their condition in the modern healthcare system. In the past, the self-management component was less or missing in diseases like flu and communicable disease but the '***chronic disease'*** we are facing in the 21st century, is what we '***live with'*** required self-management.

Self-management of chronic illness has been widely recognised as an essential part of chronic illness care, as it empowers patients and improves health outcomes (van Houtum, Rijken, Heijmans & Groenewegen, 2013). Self-management includes managing symptoms, treating the conditions, making lifestyle changes and coping with the physical

and psychological consequences of having a chronic condition (Rijkin, Jones, Heijmans & Dixon, 2008).

With an increase in ageing population and changing lifestyles, the incidence and prevalence of long-term conditions are increasing worldwide (WHO, 2011). Living with a chronic disease has a huge impact on the health care services. In the UK, 17.5 million adults are living with chronic diseases, and by 2030, it is estimated that the incident of chronic conditions in those over 65 years will more than double (DoH, 2013).

Diabetes is a chronic condition that demands medical care along with self-management. An epidemiological trend indicates there is a steady increase in developing diabetes around the world in the past few decades (WHO, 2016; Diabetes UK, 2012; Kntish, 2016). Globally, an estimated 422 million adults were living with diabetes in 2014 (WHO, 2016). In the UK alone, 4 million people are living with this condition, and another million people have diabetes but do not know it. However, people belonging to South Asian descent are at higher risk of developing this condition. In the UK, people from the South Asian community have a six times higher risk of developing type 2 diabetes and at the younger age of 25, opposed to 40 in the indigenous UK population (Diabetes UK, 2014). In recent years, there has been an increase in numbers of type 2 diabetes in children too. In 2000, there was the first case of childhood type 2 diabetes diagnosed in the UK and today; there are more than 500 children diagnosed with type 2 diabetes (Kntish, 2016).

An increasing number of people living with diabetes and its complications are likely to place a huge burden on health care resources. In the UK, the financial implications of diabetes to the NHS are £ 10.3 billion, which is 10% of the total NHS budget (Kntish, 2016). Over the next 25 years it can rise to £16.9 billion that means the NHS would be spending 17% of its entire budget on the condition (Diabetes UK, 2012).

The cost of treating diabetes complications is expected to almost double from the current total of £7.7 billion to £13.5 billion by 2035/6 (Diabetes UK, 2012). Diabetes therefor has a tremendous burden on the NHS that will prove challenging to fund in for both the current regime and in the future. Greater emphasis on preventive measures with rational planning and allocation of resources is required to tackle this problem. It could be more cost effective to change the lifestyle now and prevent the development of diabetes and its associated complications.

The challenge of living with diabetes should not just be left to healthcare professionals to handle; resources need to be targeted towards the right direction in prevention and treatment of diabetes. Building capacities of individuals and communities to become aware of healthier choices can be more cost effective and have a long lasting impact in the promotion of health. In this regard, developing the interventions to enhance health literacy levels in individuals not only benefits the promotion of health but also can be effective in the better management of diabetes. There is sufficient research evidence available about the association between health literacy and diabetes management (Gazmararian et al., 2003; Dewalt al., 2007; William et al.,1998; Kim et al., 2004). Health literacy has been theorised to be one of the important, non-clinical factors that can reduce the risk of developing complication in diabetes (Schillinger et al., 2002; Laramee, Morris & Litterberg, 2007).

Health literacy in the context of diabetes management includes a constellation of skills that are critical to patients in managing their condition and navigating health care services. These skills include cultural and conceptual knowledge; aural and oral literacy (listening and speaking); print literacy (writing and reading); and numeracy (ability to use and understand numbers) (Baily, Brega, Crutchfield, Elasy, Herr & Kaphingst et al., 2014).

Health literacy skills specific to diabetes management include: reading labels on pill bottles; following written and verbal instructions; comprehending appointment information; educational brochures; and informed consent documents (Schillinger et al., 2002). Numeracy is fundamental to diabetes self-management in understanding medication dosage, test results, insulin requirement and interpreting food labels (Osborn, Cavanaugh, Wallston & Rothman, 2010).

However, considering the complex nature of health literacy as a concept goes beyond a personal capacity building approach and a shared responsibility between society and individuals are needed. Development of the interventions to improve health literacy should be directed towards individuals, health care professionals, and policy makers within different cultural contexts and situations/conditions to have the more comprehensive understanding of this complex concept.

There are few qualitative studies that explore and explain health literacy practices, particularly the use of participatory approaches. However, Estacio, Saidy-Khan, Karic, McMkinley, Sargent and Murray (2012) conducted a study with people at high risk of developing diabetes that includes two groups 1) Young English men under age 30 years old; 2) South Asian men, that highlight the concern of limited health literacy in South Asians. To the best of my knowledge, this is the first study that aims to explore the health literacy needs of South Asians, which includes both males and females with particular reference to diabetes management. It is important to engage participants in more meaningful ways in this dialogue. Particularly to understand barriers to treatment adherence and to develop shared treatment plans within the context of patients' daily lives. Researcher is exploring the cultural perspective embedded within their daily lives in the management of diabetes and further exploration of their health literacy needs. This was an

opportunity to facilitate the people of South Asians community to understand their health literacy needs and how that can be met as part of self-management of diabetes with an improved quality of life.

1.2   Conceptual framework

Health literacy has been defined by WHO (2015) as:

> "the personal characteristics and social resources needed for
>
> individuals and communities to access, understand, appraise and
>
> use information and services to make decisions about health"
>
> (WHO, 2015).

Public Health England (2015) also set an agenda to have local actions embedded in the lives of individuals and communities. The protocol for this agenda not only highlights the need to have targeted actions to improve health literacy for the people who are at risk of limited health literacy. It considers the wider social and community resources within the broader aim of developing the health literate population and reduces health disparities. Health literacy is thus considered as an empowerment tool to reduce the health inequalities in vulnerable groups. It is stressed to have actions at the local level to improve the health literacy of disadvantaged or vulnerable groups embedded within a broader strategy: a) improve the health literacy of health and social care systems, b) address the conditions in which people are born, grow, live, work and age.

However, there is still research evidence needed to assess the health literacy initiatives among disadvantaged individuals/communities and to understand the role of health literacy in reducing health inequalities.

1.3   Aims of the thesis

The thesis aims are outlined below:

- There is limited data about health literacy levels in ethnic communities in the UK. Considering the complexity of health literacy as a construct, the aim is to illustrate the relationship between health literacy and demographics (Age, gender, education), health outcomes (health status, quality of life), and mediating factors (Self-efficacy) to contribute to the research evidence in this matter.

- Taking into consideration that the concept of health literacy is very sensitive to context and culture, in this thesis, the aim is to explore the participants' daily management of diabetes and their health literacy needs through the participants led approach to gain an understanding of their unique cultural perspective in this matter.

- Taking into account the need for specific interventions to improve the health literacy of people from ethnic groups, in this thesis, the aim is to present research-based recommendations specific to diabetes management in the South Asians in the UK to improve self-management and health literacy to improve their quality of life while living with diabetes. The findings of this research thus enable us to identify the barriers in reference to this community that will be helpful to close the gap between the demands of modern healthcare and people's abilities in reducing the health inequalities and strengthen the well-being of individuals and communities.

1.4 Structure and overview of the thesis

Following this introductory chapter there are six chapters:

1.4.1 Chapter 2 General background to health literacy

This chapter presents a general introduction to health literacy. It presents the reviews of different definitions of health literacy, followed by a dual approach to define health literacy. Different health literacy frameworks are presented to showcase different aspects of health literacy, followed by measurement of health literacy. The importance of health literacy covers the prevalence, associated health outcomes, self-management along with implications in the health care process. The last section of the chapter places health literacy into health inequalities context along with discussing ethnicity and how it informs the implications for the health literacy framework used in this research.

1.4.2 Chapter 3 South Asians, diabetes and health literacy

This chapter starts with a discussion of South Asians as an ethnic community in the UK. Then an introduction to diabetes will be presented with its global prevalence and classifications of different diabetes conditions were discussed.

Next, diabetes is explored within the South Asians perspective by discussing; prevalence and risk factors of developing diabetes in this community. The prevention and management of diabetes is presented followed by the role of health literacy within the context of debates complications, self-management and how health literacy and diabetes self-management can be improved. Health literacy and diabetes management have also been discussed along with the empowerment, self-efficacy and quality of life.

1.4.3 Chapter 4 Research framework and methodology

This chapter starts with a brief introduction of qualitative and quantitative methodologies and sets a rationale for using mixed methods approach to achieve the aims of this thesis. The mixed methods approach is discussed with its philosophical basis pragmatism, followed by different mixed methods. Mixed methods as a methodology in this research along with ethics have been discussed. The methods used in both studies were presented. A survey with a brief introduction and how it has been used in present research, followed by with a brief introduction to photovoice and its application in present research were discussed. In the last section of this chapter the validity/reliability followed by a reflexive position in this research were presented.

1.4.4 Chapter 5 Health literacy survey

This chapter presents results of study one. Participants' demographics, the level of health literacy and its exploration with other variables have been analysed. Results about the quality of life of the participants with diabetes were also presented. Discussion of the quantitative findings is also presented in this chapter.

1.4.5 Chapter 6 Exploring health literacy through Photovoice

This chapter presents the results of the qualitative study (photovoice). In this chapter, the participant's narratives and images were discussed, and details on themes that have emerged from the thematic analysis are provided, followed by the discussion on the findings.

1.4.6 Chapter 7 Final discussion

This chapter presents an overall discussion, which relates to both of the two studies that

comprise the thesis. This chapter also reflects on the contribution to knowledge with recommendations to theory and policy. The strengths and limitations of the research were also discussed, along with future research recommendations followed by a final conclusion of this thesis.

2   General Background to Health Literacy

2.1   Introduction

The field of health literacy has evolved over the decades, and the term has been increasingly used in healthcare research and policy (DeWalt, Berkman, Sheridan, Lohr & Pignone, 2004). The term 'health literacy' was first applied within the framework of school health education and social policy (Simonds, 1974). Since the development of health literacy as a concept there are different definitions available to describe it see Table 2.1(p.12), however, this concept still needs to be agreed on conceptualisation amongst those working in this field (Pleasant et al., 2016). Early definitions of health literacy, focused on individual skills such as word recognition; reading comprehension and numeracy; while later, system demands and complexities were also included (Ad hoc Committee on Health Literacy,1999; Institute of Medicine, 2004; WHO, 2013) along with a variety of social and communication skills (Nutbeam, 1998; Osborn, 2013).

At the individual level, health literacy was concerned about the basic abilities of an individual to read prescriptions, medicine instructions and appointment information (Parker, Baker, Williams & Nurss, 1995). Later these capacities were broadened to look at why some people adhered with the prescribed treatment more than others. It also addressed wider questions related to the understanding of the people about health related information and their engagement to have shared-decision making in managing and maintaining their health. In this way, health literacy has been a conceptualised form of sociological approaches to the disease and healthcare within the daily lives of the individuals (Bennett & Perkins, 2012).

Table 2.1: Definitions of health literacy

AMA (1999)	"The constellation of skills, including the ability to perform basic reading and numerical tasks required to function in the health care environment" (p. 553).
Nutbeam (2000)	"The personal, cognitive and social skills, including the ability to perform basic reading and numeracy tasks required to function in the health care environment" (p. 357).
IOM (2004)	"The individual's capacity to obtain process and understand basic health information and services needed to make appropriate health decisions" (p. 5).
Kickbusch, Wait, Maag & Banks (2005)	"The ability to make sound health decision (s) in the context of everyday life at home, in the community, at the workplace, the healthcare system, the marketplace and the political arena. It is critical empowerment strategy to increase people's control over their health, their ability to seek out information and their ability to take responsibility" (p. 8).
Zarcadoolas, Pleasant & Greer (2006)	" The wide range of skills, and competencies that people develop to seek out, comprehend, evaluate and use health information and concepts to make informed choices, reduce health risks and increase the quality of life" (p. 55)
Paasche-Orlow & Wolf (2006)	"An individual's possession of requisite skills for making health-related decisions, which means that health literacy, must always be examined in the context of the specific tasks that need to be accomplished. The importance of contextual appreciation of health literacy must be understood" (p. 20)
Rootman & Gordon-Elbihbety (2008)	"The ability to access, understand, evaluate and communicate information as a way to promote, maintain and improve health in a variety of settings across the life-course" (p. 11).

Adams et al., (2009)	"The ability to understand and interpret the meaning of health information in written, spoken or digital form and how these motivates people to embrace or disregard actions relating to health" (p. 144).
Freedman et al., 2009	"The degree to which individuals and groups can obtain, process, understand, evaluate, and act upon information needed to make public health decisions that benefit the community" (p. 48).
Sorensen et al., (2012)	"Health literacy is linked to literacy and entails people's knowledge, motivation and competencies to access, understand, appraise, and apply healthcare information in order to make judgments and take decisions in everyday life concerning healthcare, diseases prevention and health promotion to maintain or improve quality of life during the life course" (p. 3).
Osborn (2013)	"Health literacy is a shared responsibility between patients (or anyone on the receiving end of health communication) and providers (or anyone on the providing end of health communication). Both communicate in ways the other can understand" (p. 5).

The World Health Organisation (WHO) presented a wider definition of health literacy: "the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health. Health literacy is more than being able to read pamphlets and make appointments. By improving people's access to health information, and their capacity to use it effectively, health literacy is critical to empowerment" (WHO, 1998, p.10).

The definition provided by WHO, highlights that health literacy is more than the basic skills of comprehension and compliance. The WHO definition has included the empowerment theory that has become central to health literacy research (Shohet, 2002). In

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recent years there is an increased need of empowerment for patients (Meetoo & Gopaul, 2005). Therefore the concept of empowerment has become more popular in the healthcare context (Wallerstein & Bernstein, 1988). Nutbeam (2000) extended the definition of WHO by describing health literacy skills/capacities on three levels:

1. *Functional health literacy* refers to the basic reading and writing skills that can help individuals to function effectively in the healthcare context.

2. *Interactive health literacy* refers to the development of personal skills, in a supportive environment, to improve personal capacity, to enable individuals to act independently on knowledge about health.

3. *Critical health literacy* refers to the ability to critically evaluate and use information and actively participate to overcome the structural barriers to health.

In the developed countries a high level of literacy is essential to fully function in the society. As in previous decades, most of the research in the field of health literacy has been conducted within the Unites States of America (USA) and shows that health literacy is affected by basic literacy and numeracy skills (Williams, Baker, Parker & Nurss, 1998; Schillinger et al., 2002). However, it is important to note here that the terms 'literacy' and 'health literacy' are not automatically interchangeable. The 'health literacy' concept can be traced back to basic literacy skills such as reading and writing but it is far more complex than merely literacy skills and considered a set of abilities and skills needed to assess, obtain, understand and act upon the information to maintain good health as earlier discussed in the definition of WHO (Peerson & Saunders, 2009).

The consideration of structural barriers in defining health literacy as a complex construct (Martensson & Hensing, 2011), highlights the need to consider how environment and lifestyle choices impact on health and the extent to which people are empowered to make informed choices, to protect their health and their families (Bennett & Perkins,

2012). Health-related decisions may be made by either a group of people (family, community) or an individual (Dodson, Beauchamp, Batterham & Osborn, 2014). In the same way, health literacy can be described as the shared resources of individuals and communities that influences (and is influenced by) health behaviours and the characteristics of society and the healthcare system (Sorenson et al., 2012; Freedman, Bess, Tucker, Boyd, Tuchman & Wallston, 2009). Further Simth, Nutbeam and McCaffery (2013), described health literacy as a content and context specific construct, in this way health literacy in one setting or relating to one health decision may be different from another.

Dodson et al. (2014), further explained that individuals and communities could have strengths and limitations that influence how effectively they engage with health information and services. Health and social services systems, can have strengths and limitations in how they respond to the health literacy of the people they serve (Batterham, Buchbinder, Beauchamp, Dodson, Elsworth & Osborn, 2014). Dodson et al. (2014) further explained health literacy responsiveness: that means to make health information, resources, support and environment available and accessible to people with different health literacy strengths and limitations. In line with these arguments, present research defines health literacy, according to WHO's (2015) definition that has considered both individual characteristics and community resources:

> "the personal characteristics and social resources needed for
> individuals and communities to access, understand, appraise and
> use information and services to make decisions about health"
> (WHO, 2015).

2.2   Dual approach to health literacy

2.2.1   Health literacy as a risk

The risk approach considers health literacy an individualistic construct; it also considered changes in the healthcare delivery considering the health literacy level of the individual and particularly limited health literacy.

Literacy impacts upon the health of an individual (DeWalt et al., 2004) such as less use of preventive services (Gordon, Hampson, Capell & Madhok, 2002).), more physician visits (Scott, Gazmararian, Williams & Baker, 2002), and increased risk of hospitalization (Baker et al., 2002). People with limited literacy skills also have poor adherence with treatment plans (Kalichman et al., 1999) and worse disease management (Williams et al., 1998). Such trends pave the ways to further research to investigate in order to mitigate its negative effects. It has been found that interventions designed to lessen the effects of low literacy can improve knowledge and health behaviour (Coulter & Ellins, 2007). People with limited health literacy face problems with managing the health care system (Baker et al., 2002; Cho, Lee, Arozullah & Crittenden, 2008; Howard, Gazmararian & Parker, 2005). This combination of cost and effect of low literacy on health has attracted the attention of policymakers and health service providers (Eichler, Wieser & Brugger, 2009).

In the USA, the literature has shown the relationship between low literacy, patient decision making, compliance with prescribed medication use (Kalichman et al., 1999), and capacity to self-management of disease (Ross, Frier, Kelnar & Deary, 2001). Health literacy is considered as a set of capacities and skills that act as a mediator in health and clinical decision making within the health care sector (Baker, 2006).

An important publication in the development of health literacy was published by the USA Institute of Medicine (IOM), in 2004 '*Health Literacy: A Prescription to end confusion'*. This report of the IOM comprised of the work done in the USA for the development of the tools to assess health literacy for clinicians, such as the Rapid Estimate of Adult Literacy in Medicine (REAM) (Davis et al, 1993) and Test of Functional Health Literacy in Adults (TOFHLA) (Parker et al., 1995). Health literacy was also discussed in association with a number of health practices and health outcomes (i.e.management of chronic medical conditions, compliance with medication and other health-related services, participation in health and screening programs) (IOM, 2004). It conceptualises health literacy, as a set of capabilities regarding cultural and social knowledge that include four domains: 1) speaking and listening skills; 2) writing; 3) reading skills; and 4) numeracy. This conceptualization of health literacy, showed that it is partly knowledge based and can be enhanced with educational interventions. It can also be affected by the structure of the health care services provided to the individuals (Nutbeam, 2008).

Baker (2006), states that health literacy has been expanded in depth and scope, it needs more clarification to overcome confusion. Health literacy is not only the capacity of individual skills, but it is also affected by the health care system and broader social factors. In such conceptualization, the individual measures and tools to assess health literacy, containing individual skills are insufficient. There is a need to develop screening tools to cover all these dimensions, to understand the gap between capacities and current demands of health promotion and disease prevention that are linked to health literacy. Paasche-orlow and Wolf (2007), presented a logical model () to explain the role of health literacy in health outcomes. Health literacy effects on health outcomes at three critical points: access and utilisation of health care services; patients and care provider interaction; and self-care. Although this model was built on the limited research data,

nevertheless it sheds light on how limited health literacy, affected through these pathways on health outcomes.

Following the information taken from the IOM report, a highlighted suggestion by Baker (2006), and finally a model proposed by Paasche-orlow and Wolf (2007), a model has been developed to represent health literacy as a risk (Figure 2.1, p. 19). It signifies the health literacy as a risk factor that needs to be identified and appropriately fingered out in clinical care settings (Nutbeam, 2008). This approach towards health literacy, puts the responsibility on individuals to navigate through the health care system. In this way, people with limited health literacy may find it hard to access and utilise health care services, and consequently, they have poor health outcomes. This approach towards health literacy revolves around clinical settings and is based on the deficit model of health that defines communities and individuals in negative terms. The health deficit model, is based on the philosophy that not performing a particular behaviour, is a deficit or problem that needs to be solved (Moore & Charvat, 2007).

Health literacy as a risk (Figure 2.1, p.19) begins with the assessment of prior knowledge and skills by using measurement tools to assess the levels of health literacy. This assessment of health literacy will increase the sensitivity of the clinical settings, about patient's level of health literacy, and improvement in assessing the sensitivity, will improve the access and utilisation of health care services. This will improve the interaction between patients and health care providers and be helpful in providing tailored information according to the needs of the patients. Adherence of the patients with treatment plans will be improved that will improve the health outcomes.

Figure 2.1: Conceptual model for health literacy as risk (Nutbeam, 2008 p. 2074)


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                    ┌─────────────────────────────┐
                    │  6. Improved Clinical       │
                    │     Outcomes                │
                    └─────────────────────────────┘
                                ▲
                    ┌─────────────────────────────┐
                    │  5. Enhanced capability for │
                    │     self-management,        │
                    │     improved compliance     │
                    └─────────────────────────────┘
                       ▲                    ▲
      ┌─────────────────────┐      ┌──────────────────────────┐
      │ 4. Tailored health  │      │ 3. Improved access to    │
      │    information,      │◄─────│    health care, and      │
      │    communication,    │      │    productive interaction│
      │    education         │      │    with health care      │
      └─────────────────────┘      │    professionals         │
              ▲                     └──────────────────────────┘
                                              ▲
  ┌──────────────────────────┐    ┌──────────────────────────┐
  │ 1. Health literacy       │    │ 2. Organizational        │
  │    assessment            │───►│    practice              │
  │ Health related reading   │    │                          │
  │ fluency, numeracy, prior │    │ Sensitive to health      │
  │ knowledge                │    │ literacy                 │
  └──────────────────────────┘    └──────────────────────────┘
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2.2.2   Health literacy as an asset

According to this perspective, health literacy is seen as an asset, needs to be developed as

an outcome of the education and communication (Beric & Dzeletovic, 2003) that enables

and empowers individuals, to make decisions about health. Health literacy as an asset

focuses on developing age and context specific knowledge for the individuals to enable

them to make informed decisions and take control of their health (Nutbeam, 2000).

This approach evolved from the contributions of public health and health

promotion, to develop competencies through education and communication for different

health care actions. This approach not only includes the personal skills to empower the

individuals but also considers the other social, personal, and environmental determinants of health (Nutbeam, 2008).

This approach towards health literacy identified it as a distinctive concept rather than a derivative concept from literacy and numeracy. The asset model is based on the salutogenesis, first presented by Antonovsky (1996). It emphasises the success rather than failure. It also searches for the foundations of positive patterns of health, rather than the foundation of negative health outcomes. Health literacy as an asset, focused on to develop age and context specific knowledge for the individuals, in combination to have self-efficacy to put all this knowledge into practice, to make appropriate decisions and take control of their health (Nutbeam, 2000). This perspective of health literacy, has its roots in educational research in literacy and concepts of adult learning and health promotion (Freebody & Luke, 1990; Imel, 1998).

The asset approach of health literacy, emanated mainly from the United Kingdom (UK), Australia and Canada and research is in progress to conceptualise health literacy as an asset (Rootman & Ronson, 2005; Coulter & Ellins, 2007; Renkert & Nutbeam, 2001). The asset approach conceptualised health literacy differently than the risk approach, and the WHO definition of health literacy, reflects the public health orientation that is subtly different to the IOM definition of health literacy:

'The cognitive and social skills which determine the motivation and ability of individuals to gain access to understand and use information in ways which promote and maintain good health' (WHO, 1998, p.10).

As discussed earlier, the WHO definition describe health literacy, as the achievement of knowledge, personal skills and confidence to take action to improve personal and community health, by changing personal lifestyle and living conditions.

Health literacy is more than being able to read the health care information and making the appointments. By improving the people's access to healthcare information and building their capacity to use it effectively, health literacy is critical to empowerment (Nutbeam, 1998).

As discussed earlier, this typology of health literacy (p. 14) reflects the progressive development of the concept of health literacy. It reflects the skills, which enable individuals to have greater autonomy and personal empowerment, in taking decisions and engagement in taking social actions, within the wider social environment, to address the determinants of health (Nutbeam, 2000).These progressive levels for health literacy show that the personal response of an individual is affected by personal and social skills, the communication and content of the messages and self-efficacy.

The conceptualization of health literacy, as empowerment through the development of interactive and critical skills, has an important implication for the scope of content for health education and communication. In this regard, health education is not about to develop personal skills to change lifestyles and develop compliance to disease management strategies, but it should also focus on ways to raise awareness about the social determinants of health and how that can be modified. Educational content in this regard needs to be broadened to include genuine options for self-management of disease, the skill development that enables individuals to interact with the health care providers and the ability to navigate through the health care system (Nutbeam, 2008).

This understanding of health literacy, identifies it as an asset that can be developed and improved through education and communication throughout the life of an individual (Figure 2.2, p. 22). This model of health literacy, starts to consider the prior knowledge of an individual that leads towards the development of tailored information, communication

and education for the people. At this point, it is significantly different from the previous model (Figure 2.1, p.19), that health literacy is considered the outcome of health education and communication rather than a factor that influences the outcome. The skills and capabilities developed not only benefit on an individual level and on a broader level of participation and engagement in social actions. This skill development has far more productive effects than to health outcomes.

Figure 2.2: Health literacy as an asset (Nutbeam, 2008, p. 2076)
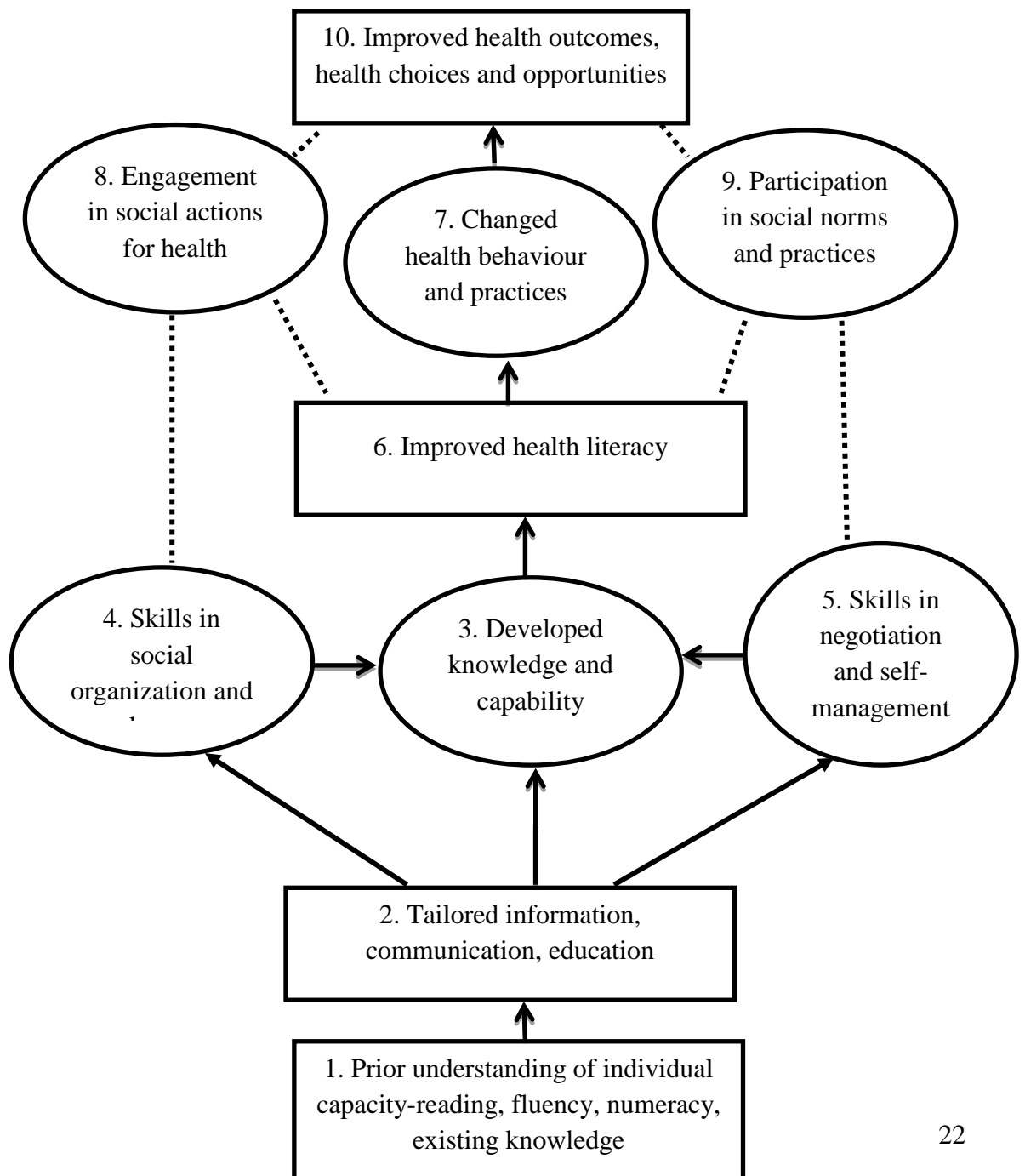
Both the conceptualisation of health literacy as a *'risk'* and an *'asset'* are important; the risk approach mainly developed in the USA, reflected the recognition of the impact of low health literacy on health outcomes (Baker, 2006; Paasche-Orlow & Wolf, 2007). It helped to develop the interventions, to improve the sensitivity of the health care organizations and professionals, about the effects of limited literacy on health decision making and compliance (Coulter & Ellins, 2007; Pignone et al., 2005; Rootman & Ronson, 2005). Research conducted in 'health literacy as a risk approach' made important progress to address the sources of disadvantage and inequity in the healthcare system and suggested that improvement made in patient education and management being achieved in the United States, needs to be tested more widely (IOM, 2004).

However, Nutbeam (2008), considered health literacy as a risk approach with limited outcomes, while health literacy as an asset, can have more comprehensive options for support, to build health literate individuals and communities. It can help better self-management, enable the development of skills, to foster confident interaction with the healthcare professionals and the ability of the patients to navigate and negotiate within the healthcare system. In addition, the asset approach, can have broader application going beyond to health care settings; for example: into schools, adult learning and community development programs and can be helpful to reduce health disparities through improved health literacy. There is a need to investigate further the capacity building approach of health literacy, and how that can be integrated within the health system and other systems of society to create healthy individuals and communities. This approach of developing personal capacities of individuals and communities along with the clinical perspective of health literacy is further explored in this thesis; that how health literacy can enable the individuals to have better self-management of diabetes with good quality of life. Different frameworks to describe and explain health literacy were presented in the next section.

2.3 Health literacy frameworks

In the literature, different models appear to define changing approaches towards health literacy and its process. No single model can comprehensively capture the evolving definitions of health literacy with the competencies it implies (Protheroe,Wallace, Rowlands & Devoe, 2009). In this section different frameworks of health literacy are discussed. The multidimensional conceptual framework (Zarcadoolas, Pleasant & Greer, 2005), presents different dimensions of health literacy, Mancuso (2008), model discusses the concepts with different competencies. Health literacy with health outcomes, has been shown through the model of Paasche-Orlow and Wolf (2007), and how health literacy can reduce health disparities presented through the model by Pawlak (2005). Edwards, Wood, Davies and Edwards's (2012) situates health literacy in the perspective of long-term conditions and how this can be achieved with support from others as a lifelong process. The last model presented here is an integrated model of health literacy developed by Sorensen et al. (2012) that outlines different dimensions, skills, and competencies of health literacy and its associated social and health outcomes.

Zarcadoolas et al. (2005), proposed a multidimensional framework of health literacy, characterised by four domains: 1) fundamental literacy; 2) science literacy; 3) civic literacy; and 4) cultural literacy. They described the wide-range of skills and competencies that people develop to seek out, comprehend, evaluate and utilise health care information and make informed choices to reduce the health risks. The first construct of this model is *fundamental health literacy;* which focuses on reading, writing, speaking and interpreting numbers. *Science literacy* involves the understanding of scientific concepts and processes; while *civic literacy* deals with the understanding of civic and governmental health care policies. Civic literacy develops skills in individuals, to have the abilities to be

aware of the public issues and become actively involved in decision making. The *cultural literacy* is the recognition of collective cultural beliefs, customs, and social identity to interpret and act on health care information and its accommodation in a health care setting. This framework presented different domains of health literacy, that should be considered in developing interventions to improve health literacy. In relation to present research, including other domains, the concept of cultural health literacy is important to explore as South Asians have distinctive cultural norms and traditions that can have huge implications for health and disease management.

Mancuso (2008) carried out a dimensional concept analysis of health literacy. A clear understanding of the concept of health literacy is essential as it has greater implications that impact both on the individual and society. According to Mancuso, an individual must have certain skills and abilities, which are necessary to attain health literacy competencies. Competence implies having the capability to function effectively in health care settings. He described six dimensions of health literacy competencies: 1) *Operational competence* is the ability to utilise tools, procedures, and techniques for handling language proficiency (Kerka, 2003); 2) *Interactive competence* is the collaboration of one with others for individual improvement and enhancement through self-management; 3) *Autonomous competence* is the personal empowerment that enables an individual to take decision related to his health; 4) *Informational competence* entails the ability needed to recognise a health information need, a strategy to identify the likely sources and use them to retrieve relevant information; 5) *Contextual competence* is considered the mastery of the environment and it suggests that individual will learn best when learning is situated through interacting with and interpreting content within a familiar environment; 6) *Cultural competence* is the ability to interpret the meaning system of social practices and individuals possess the skills needed to recognise and use collective

beliefs, customs and social identity, to interpret and act on health information (Zarcadoolas et al., 2006). He described characteristics of health literacy 1) capacity; 2) comprehension; and, 3) communication; and these attributes get affected by the antecedents. The outcomes of the health literacy depend upon whether one has achieved adequate or inadequate health literacy and had the potential to influence individuals and society (see Figure 2.3).

Figure 2.3: Health literacy: A concept model (Mancuso, 2008, p. 251)
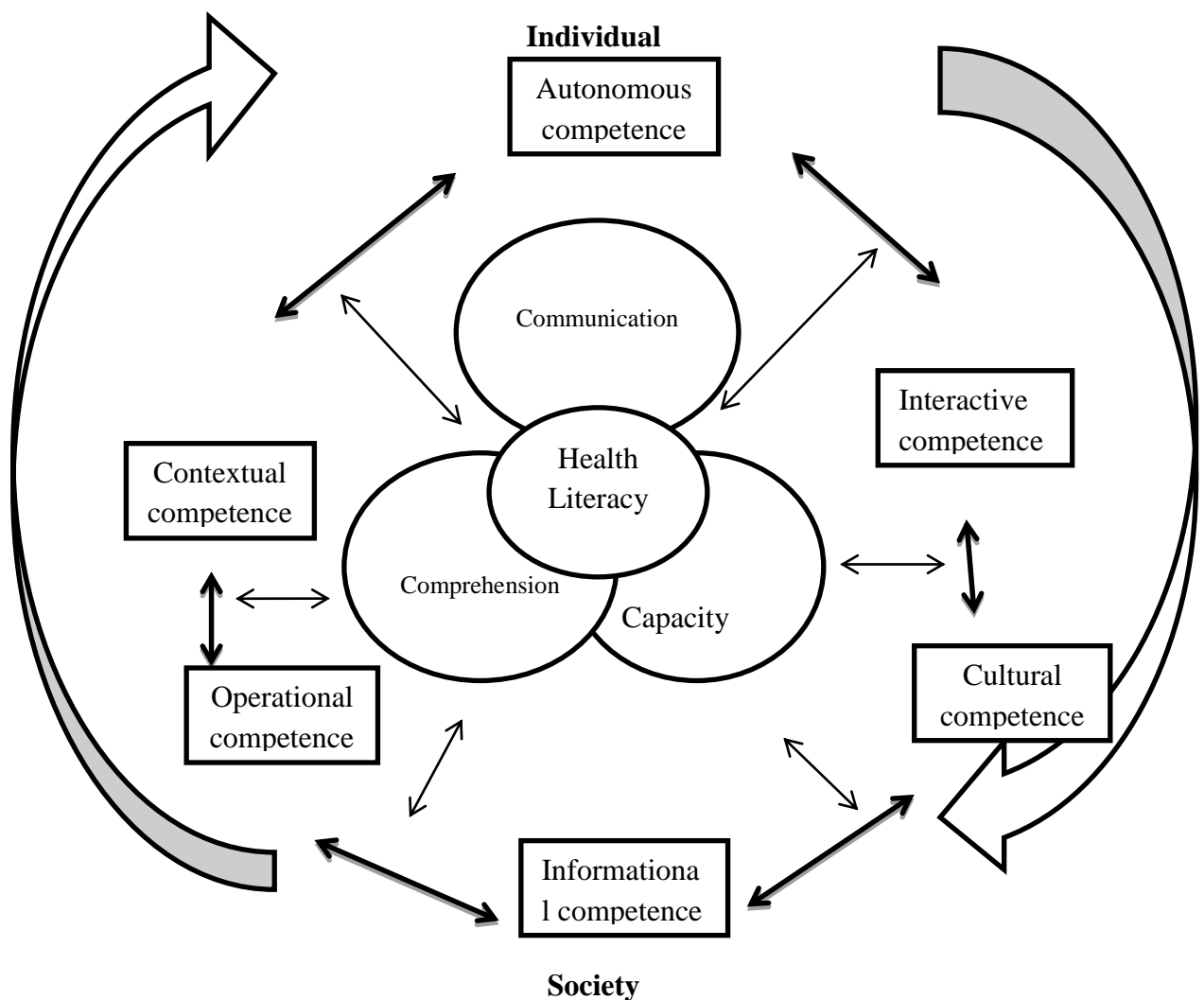
The Paasche-Orlow and Wolf (2007) model (Figure 2.4, p. 28) explained the well-established association between limited health literacy and health outcomes. It also highlights the contextual appreciation of health literacy. The concept of health literacy, includes multiple elements (listening, verbal fluency, memory span, navigation) and it is

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also strongly associated with other socioeconomic indicators, including educational attainment, race/ethnicity, age, social support and employment status. According to this model, health literacy should be viewed as both a patient and system phenomena, and places health literacy as a risk approach. The causal mechanisms of health literacy and health outcomes relationship are not only due to patient level characteristics, but attributes of the health system are also important to consider in this regard. Therefore the proposed causal conceptual model, recognise both individual and system-level factors that affect access to health care, medical encounters and self-care activities. This causal model has combined the different domain and causal factors, between health literacy, and health outcomes, although it still has some limitations. This model considered health literacy as a fixed skill and did not consider different dimensions of health literacy as Nutbeam (2000), considered three levels of health literacy (functional, critical and interactive). On the other hand, it lacks the complex interaction of the causal factors link with health literacy. There is lack of clinical evidence to understand the complex interaction of these causal factors on health literacy and health outcomes as discussed in the model of Paasche-Orlow and Wolf (2007).

Figure 2.4: Causal pathway between health literacy and health outcomes (Paasche-Orlow & Wolf, 2007, p. 21)
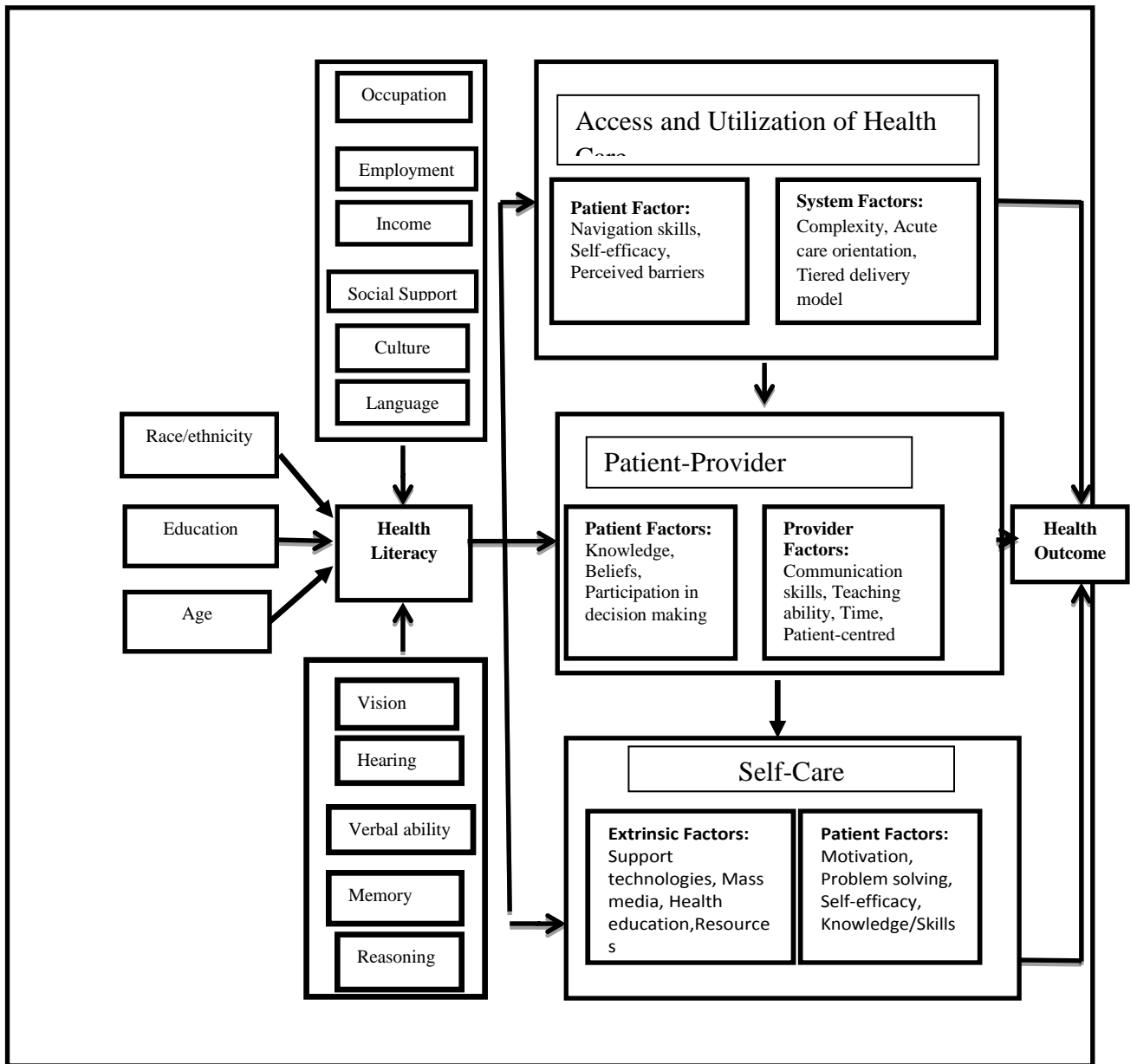
Pawlak (2005) developed a model that depicted the determinants of health literacy and how the level of health literacy affects within the healthcare settings that further reduce health disparities in societies and consequently improve population health (Figure 2.5, p. 30). According to this model, the level of health literacy, can be determined by different factors including; age, genetics, language, race, education, employment, socioeconomic

status and environment. As health literacy improves, it is theorised that improvement can be seen in the reduction of health disparities and improved health of the population. This model places health literacy, in the centre of the other determinants of health. Determinants that impact on the level of health literacy individually or in combination with others are outlined in the left. The level of health literacy of an individual consequently effects on the capacity of obtaining, processing and understanding health information and services needed to make appropriate health decisions.

In the health care settings it affects: (1) *On the level of care* that matched with need; e.g. an individual is seeking primary care when primary care is needed; (2) *Improved communication with payer and provider* e.g. navigate the health system, insurance policies and ability to follow the treatment plans; (3) *Informed consumer* e.g. knowledge and information, skills for self-management, use of preventive services and other health services when needed, self-advocacy and ability to manage language, written material, and technology; (4) *Treatment compliance,* e.g. person understands the rationale of the treatment, can search for related therapies and have motivation and skills to comply with the treatment.

Improvement in any of this, or all, can reduce the health disparities in society, and that can lead towards the improvement of population health in society. The strength of this model is that it linked with various determinants of health literacy and health outcomes. This is helpful in framing strategies to improvement, in multiple areas, of health literacy that can reduce health disparities. This model based on the health care and health services of the USA, thus, lacking the research evidence in the perspective of other health care systems in different countries. It also fails to address that how the sources of information may influence an individual's experiences in accessing and understanding information.

Figure 2.5: Determinants of health literacy: A determinant of population health (Pawlak, 2005, p. 177).

Age

Genetics

- Cognition
- Ability

Language

Race and Ethnicity

- Culture

Education

- Reading level
- Technologies
- Competence

Employment

Socio-economic status

Environment

- Access to care and technology

Health Literacy

Level of care matched with need

Improved communication with payer and provider

Informed consumer

Treatment compliance

Improved Population Health

Reduced health disparities

Edwards et al. (2012), present the health literacy pathway model (Figure 2.6, p.31) that shows how health literacy develops along a trajectory that enables individuals, supported by others, to seek, engage with and act on health information; to manage their health and become more actively involved in health care consultations, in the context of various long-term conditions. This model is based on the asset approach towards health literacy. Thus the focus is not on the inadequate health literacy but the development of health literacy over time for the people of all health literacy abilities through self-learning and patient education. In this model, the facilitators and barriers along the pathway towards improving health literacy are identified. The stages of the process of developing health literacy in patients with long-term medical conditions are presented by mapping a health literacy pathway from health knowledge towards decision making. This model includes five stages along a pathway; each stage requires a more complex set of health literacy

skills. Health literacy processes are represented in the five stages of the pathway model, and health literacy outcomes are represented as running parallel to those stages.

Figure 2.6: The health literacy pathway model (Edwards, Wood, Davies & Edwards, 2012, p. 15).
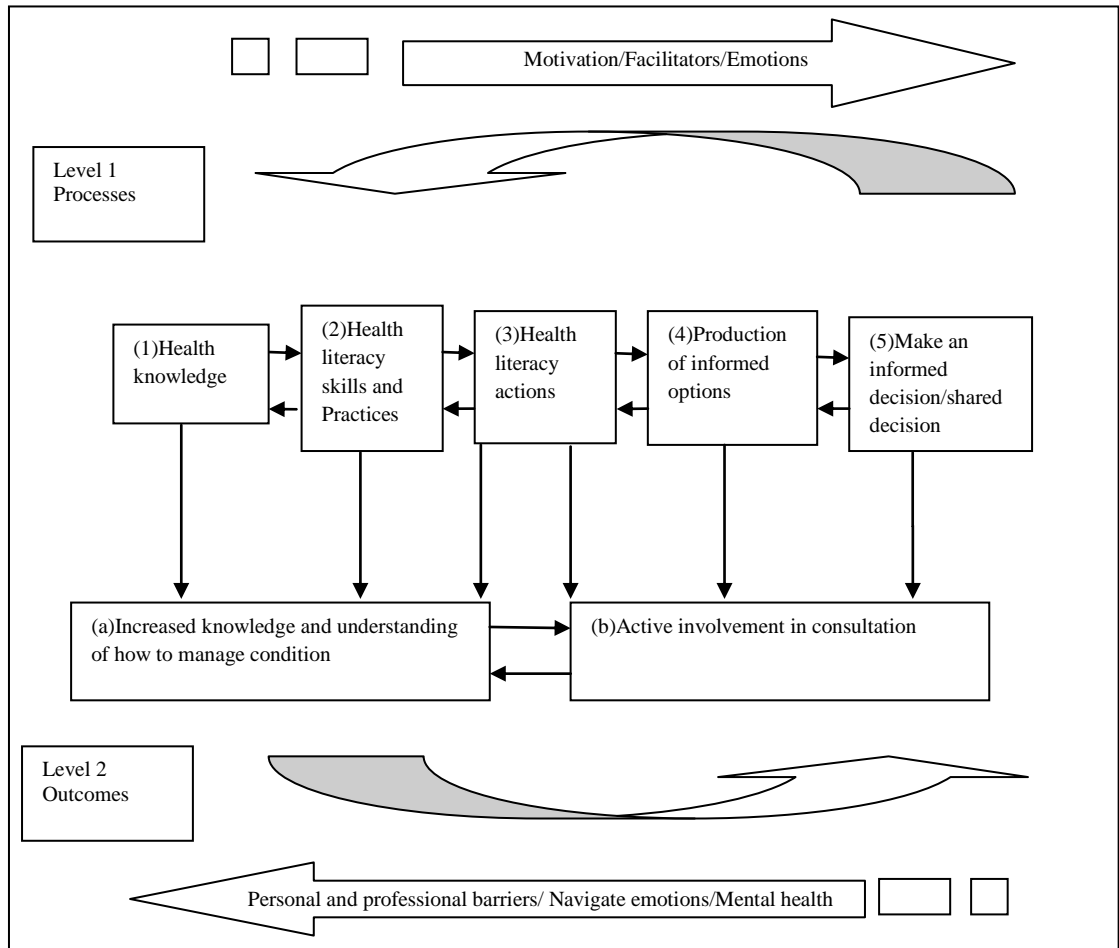
Sorensen et al. (2012), critically reviewed the existing models and definitions of health literacy and stated that there is limited work on the integration of different perspectives to define health literacy. The model (Figure 2.7, p. 33), presented by Sorensen et al. (2012) combines the qualities of a conceptual model outlining the main dimensions of health literacy, showing the proximal and distal factors which impact on health literacy, as well as the pathways, link to social and health outcomes. Sorensen et al.'s (2012) model of health literacy integrates the medical and public health views of health literacy and covers different dimensions of health literacy concerning healthcare, disease prevention

and health promotion. The core of the model shows the competencies related to the process of accessing, understanding, appraising and applying health care information: that includes four type of competencies: (1) *access* refers to the ability to seek, find and obtain health information; (2) *understand* refers to the ability to comprehend the health information that has been accessed; (3) *appraise* describes the ability to interpret filter, judge and evaluate the health information that has been accessed; and (4) *apply* refers to the ability to communicate and use the information to make a decision to maintain and improve health.

All these competencies also incorporate the qualities of functional, interactive and critical health literacy described by Nutbeam (2000). These competencies enable people to navigate three domains of the health continuum: being ill or as a patient in the healthcare settings, as a person at risk of disease in the disease prevention system, and as a citizen in relation to the health promotion efforts in the community, the workplace, the educational system and at marketplace. The framework associated with the three domains represents a progression from an individual towards a population perspective. As such the model integrates the medical conceptualization of health literacy with the broader public health perspective. Health literacy benefits on individual and population level, it influences health behaviours and the use of health services and thereby will impact on health outcomes and health cost in society.

Figure 2.7: Integrated model of health literacy (Sorensen et al. 2012, p. 9).
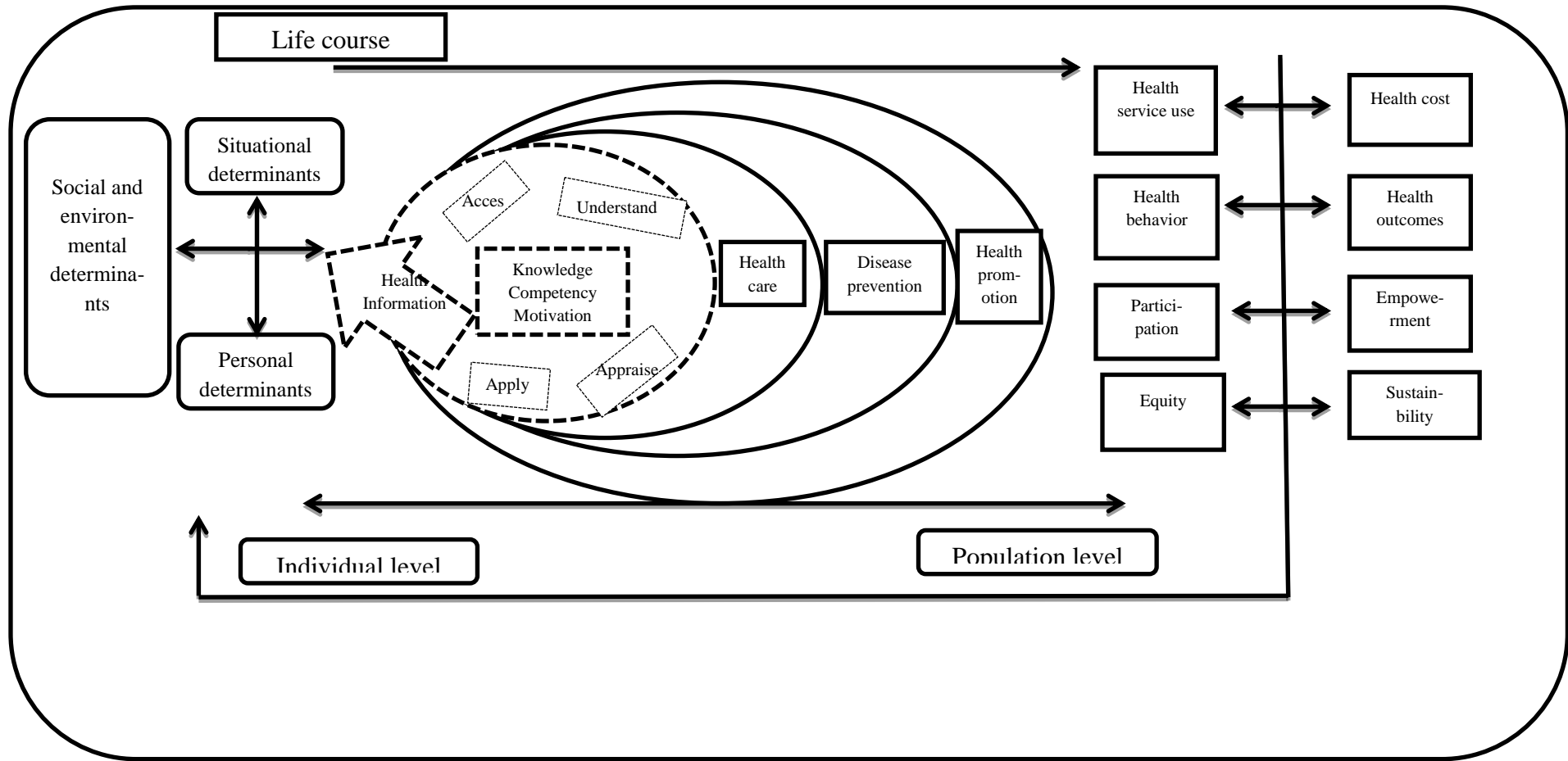
Different models were presented to showcase the complexity of health literacy as a concept and further, thus suggest, the classification about the capacities and skills as part of health literacy. This has been identified through different models and frameworks and shown that health literacy is context specific concept and can be conceptualised differently within different settings and contexts. Squires, Peinado, Berkman, Boudewyns and McCormack (2012), criticise the available models of health literacy, indicating that few of the models illustrate the full continuum of relations among predictors, moderators and mediators, and outcomes of health literacy in one model or framework. For example, the Mancuso (2008) model places more focus on factors that influence the development of health literacy. Paasche-Orlow and Wolf (2007), focus on the pathways between health literacy and health outcomes; and Pawlak (2005), linked it to reduce health disparities. The integrated model, presented by Sorensen et al., (2012), acknowledged some determinants of health literacy, along with general pathways between health literacy and population-level health outcomes, but it also does not specify the mediators between health literacy and associated outcomes. However, the model presented by Edwards et al. (2012) focuses on the development of health literacy in long-term medical conditions by placing more focus on the experiential learning and improved health literacy with the support of others. It puts health literacy in the asset perspective and considered social support as a mediator in developing health literacy levels.

It is important to make further theoretical contributions in defining health literacy, as a holistic concept in one theory or model. However, Pleasant et al. (2016), have consensus over the issues that "we encourage all participants in the field of health literacy, to realize and fully grasp the greater truth, that what counts are, not claims of priority or of being correct-what counts is how significant of the contribution in the field of health literacy, collectively makes in the world's health status" (Pleasant et al., 2016, p. 4). These

efforts needed to reflect, through the contribution of improved health literacy in the elimination of health inequalities, in enhancing the effectiveness of our current sick and health care systems in diagnosing and treating health conditions, and in the cost-effectiveness of all those efforts. In the present research, the aim is to focus on the health literacy in ethnic communities in the UK, with the aim on the greater emphasis to reduce health inequalities. The resource material presented by Public Health England (2015), is used as a framework (see Figure 2.9, p. 61), to explore how health inequalities can be reduced through improved health literacy, that is presented in section 2.6 (p.55) of this chapter.

2.4   Measurement of health literacy

This section discusses the measurement of health literacy. As discussed earlier in the section on definitions and frameworks, initially health literacy was considered an individual construct and so the early work of measuring health literacy, also focused on the functional capacities of the individuals. Later, few wider scales were developed to measure health literacy but there is still work needed in this area. In this research, health literacy has been measured in a functional and wider health literacy context, so the measures of functional health literacy and wider health literacy were described.

2.4.1   Functional health literacy

The Rapid Estimate of Adult Literacy (REALM) is the first assessment tool to measure health literacy (Davies et al., 1993). REALM, was designed to be used in primary care and public health settings to identify patients with low reading levels. The REALM is a measure of word recognition and reading ability to identify patients with low literacy levels. Davies et al. (1993) and Bass, Wilson & Grifith (2003), subsequently developed a

shortened version of REALM and revised REALM (REALM-R). However, these three forms of the REALM do not measure the understanding of the words; they only measure the sight-reading ability to identify those who are at risk for poor health literacy (Mancuso, 2009). The REALM-R, also has not been tested beyond the pilot study and further studies are needed to establish validity and reliability of this test. These tools are available in the English language and translation into other languages may enhance its validity and reliability. However, Parker et al. (1995), reported their translation of REALM into Spanish was unsuccessful due to the phonetic structure of the Spanish language.

The Test of Functional Health Literacy in Adults (TOFHLA) (Parker et al., 1995), was designed to measure functional health literacy in clinical practice and has since been used in research. TOFHLA tests a patient's ability to read passages and phrases containing numbers using real material from the health care settings. The test consists of two timed parts: (i) numeracy, which assesses a patient's ability to use numerical skills to comprehend directions; and (ii) reading comprehension. In 1999, abbreviated versions of TOFHLA were developed by Baker, Williams, Parker, Gazmararian and Nurss (1999). These authors developed two abbreviated versions: the brief-TOFHLA and the short-TOFHLA. The brief-TOFHLA, consists of two reading passages and four numeracy items, while short TOFHLA only has two reading passages. Paasche-Orlow and Wolf (2007), noted that REALM and TOFHLA are not testing health literacy, rather both can be considered as measures of basic literacy skills within a healthcare context.

Hanson-Divers (1997), developed the Medical Achievement Reading Test (MART). It is a word recognition test and is based upon the Wide Range Achievement Test (WART). MART, designed to overcome the three reasons posed by REALM: (i) use of medical language; (ii) small printing level; (iii) glossy cover that creates a glare that makes reading difficult. MART is easy and quick to administer. However, MART does

have some limitations, such as, it only assesses the word by sight not with understanding.

The Newest Vital Sign (NVS) (Weiss et al., 2005), is a 6-items functional health literacy assessment, that is structured around the activity of reading and demonstrating an understanding of information, including on a nutrition label. In comparison to the REALM and TOFHLA, the NVS has a high sensitivity to detect limited, functional health literacy, while it is less sensitive in classifying adequate, functional health literacy, against the other two measures. Osborn et al. (2007), concluded that scores on the NVS, have also been found not to be associated with health knowledge and outcomes. NVS is not a good tool for research purposes compared to the REALM and the S-TOFHLA. NVS is available in English and Spanish languages. However the psychometric properties of the Spanish version, are not as good as those of the English version, and reliability and validity are not as robust as for other instruments published in the literature (Mancuso, 2009).

Lee et al. (2006) developed the Short Assessment of Health Literacy for Spanish-Speaking Adults (SAHLSA) to screen the health literacy in the Spanish-speaking population. This is a word recognition test, based on the 66 item of REALM, which incorporates a comprehension test. To overcome the limitation associated with REALM, that merely assesses the reading ability, while SAHLSA, assesses the comprehension of the test as well. It requires the examinee, to read the word out aloud from a list of 50 medical terms, and to associate each term to another word similar in meaning to demonstrate the comprehension (Mancuso, 2009). Furthermore, SAHLSA, only measures word recognition and comprehension while it lacks numeracy assessment.

The above mentioned scales has demonstrated that existing measurement tools of functional health literacy have been useful to identify individuals who are at risk of limited skills and capacities (Paasche-Orlow & Wolf, 2007). A further consideration remains that

if health literacy is more than reading and comprehension is on the scales, to assess functional health literacy might be not sufficient. As definitions of health literacy discussed in Section 2.1 (p.10), clearly reflected a combination of complex personal and system characteristics were needed to be included to define health literacy. A person's ability to read and pronounce a word did not reflect his comprehension as measured by REALM and TOFHLA; however, NVS can be a more accurate measure of functional health literacy. Currently available measurement tools to assess health literacy do not capture all aspects and concepts discussed in the literature (Sorenson et al., 2012). Wider measurement tools to assess health literacy were needed that accurately measured: an individual's ability to access context-specific information from difference sources; a critical evaluation of information; active participation to improve personal health and community well-being and apply the information in their daily life to promote and maintain health. The wider health literacy scales were presented in the next section to showcase the development of scales within the wider perspective of health literacy.

2.4.2   Wider health literacy measures

Kwan et al. (2006) have developed a measure based on four health literacy skills: access, understand, appraise and communicate. The measure comprises two short passages for the participants to read: one is a text passage describing a self- management program for a long term condition; and the second passage describes good and bad facts and includes a food label. Comprehension is tested by posing nine questions regarding the two passages. The measure developed by Kwan et al. was found to have validity and more reliability than REALM, on which all the participants scored highly (Kwan et al. (2006). Despite the findings from Kwan and colleagues it is concluded that although this work had shown progress, health literacy, is still not adequately defined and even less well measured as a

complex concept.

In Japan Ishikawa, Takeuchi and Yano (2008) developed a measure of the broader concept of health literacy as defined by Nutbeam (2000), including communicative and critical health literacy. These constructs include the ability to extract, understand and utilise health-related information. However, the authors argued, that it is a self-reported scale that might overestimate the health literacy level of the participants, because of the shame and embarrassment associated with poor reading ability. The scale is in its early stage of development that merely administered on a Japanese sample of the population. Furthermore, it has not been compared to other validated scales to assess health literacy, and it is suggested that there is a need to refine and validate this scale for measuring communicative and critical health literacy, in other settings and with other samples of the population (Ishikawa, Takeuchi and Yano (2008).

Sorensen et al (2012) developed Health Literacy-EU Scale (HL-EU), covering the complexities of the concept of health literacy. This is a content and context-specific measure of health literacy that covers three matrixes: health care; disease prevention; and health promotion and measures the fit/relation of personal/individual competencies, expectations and experiences, versus situational/contextual demands/expectations/ complexities (Parker, 2000). Three versions: HLS-EU-Q86; HLS-EU-Q47 and HLS-EU-Q16 are available. This scale has been translated into ten languages and more work of translation in other language is in progress. This scale has been applied in the HLS-EU survey (2012) plus in additional studies with more in progress.

To date most health literacy assessments give more an indication of patients' reading level and are unable to explain the complex range of skills needed to be health literate. Baker (2006) made an argument in this context ''if health literacy is a capacity of a

person, measures of an individual's reading ability and vocabulary are appropriate. In contrast, if health literacy depends on the relationship between individual communication capacities, the health care system and the broader society, measures at the individual level are clearly inadequate'' (Baker, 2006, p. 878). Nutbeam (2000) suggests that adequate health literacy, assessed by the ability to read and write, does not guarantee that a person will respond to health education and communication strategies. Furthermore, the IOM in the USA, recommended that more aspects of health literacy, such as verbal health communication skills, cultural and conceptual knowledge, understanding of risks to health, and preventative health behaviours, should be taken into account in a measurement of health literacy (IOM, 2004).

2.4.3   Summary

This section describes the conceptual foundations of health literacy in the last few decades, further describing the measurement of health literacy. Definitions of health literacy, have been extended from a set of basic reading and numeracy skills (AMA, 1999; IOM, 2004), to more advanced cognitive and social skills to seek information (Nutbeam, 1998), and make important decisions to maintain and promote health within different settings (Kickbusch et al., 2005), and across life span (Sorenson et al., 2012). Osborn (2013), defined it as a shared process between patient and healthcare provider, and WHO (2015), defined it at a broader level, to consider individual capacities and community resources as part of health literacy definition.

Health literacy has also been studied from two perspectives: the clinical or risk approach, that considered people with limited health literacy as a problem that needs to be considered to achieve compliance with medical instructions. The other is the public health approach or asset approach, which focused to empower the individuals with improved

health literacy, through tailored education and communication to promote and maintain health. The societal and health care system's contribution is significant, along with individual factors in defining the term 'health literacy' (Kickbusch et al., 2005). Most of the research on health literacy, has been conducted within the medical perspective, taking it as a risk for the people who have limited health literacy (Scudder, 2006), and places more responsibility on the patients, to be independent and to take responsibility for their health (Osborn, 2013).

A conceptual model, presented by Sorensen et al. (2012, p.33), integrates the medical conceptualisation of health literacy, with the broader public health perspective. This model combines the qualities of a conceptual model, outlining the main dimensions of health literacy, and showing the proximal and distal factors which impact on health literacy, as well as the pathway linking health literacy to health outcomes. This comprehensive model, can be important to further explore the concept of health literacy in a public and clinical perspective.

Current health literacy measures capture the initial constructs of health literacy and measure reading and numeracy skills of the individuals. These skills are not enough to respond to health education and communication strategies (Nutbeam, 2000). This highlights the need to develop more scales that assess the system based capacities and community resources as part of the measurement of health literacy. Measures of health literacy should go beyond basic functional ability that measure interactive and critical health literacy skills of individuals.

2.5   Why is health literacy important?

This section discusses the importance of health literacy regarding the prevalence and health outcomes with particular reference to the self-management of chronic conditions. The implications of health literacy in access and utility of healthcare services is also discussed.

2.5.1   Prevalence of health literacy

Although health literacy is still a debated issue and statistics about its prevalence are limited, the association of health literacy with health outcomes is widely accepted. Research has indicated that people are not well equipped with health literacy skills and many children, adolescents and adults have limited literacy skill, even in economically advanced countries with a strong education system (WHO, 2013). In the developed world, 100 million people are functionally illiterate (OECD, 1997). In the USA, half of the American adults have limited or low literacy skills (Kirsch, Jungeblut, Jenkins & Kolstad, 1993). The Adult Literacy and Life Skills Survey (ALLS) measured the literacy of adults in Australia and recorded 40% of adults had level 2 health literacy skills (Adult literacy and life skill survey, 2006). Similar results were shown through the Adult Literacy and Life Skills Survey (ALLS), conducted in New Zealand in 2006 and reported that 56.2% of adults had poor literacy skills, scoring below the minimum level required to meet the demands of everyday life and work (Satherley, Lawes & Sok, 2006). In 2012, the Survey of Adult Skills (PIAAC) conducted in 24 countries worldwide and examined the capacity of citizens to respond new challenges of knowledge in modern society. The results from PIAAC with each country and their scores are presented on the next page (Table 2.2).

Table 2.2: Results from PIAAC (2012)

Country	Score	Country	Score
Japan	296.2	Korea	272.6
Finland	287.5	Denmark	270.8
Netherland	284.0	Germany	269.8
Australia	280.4	United States	269.8
Sweden	279.2	Austria	269.5
Norway	278.4	Poland	266.9
Estonia	275.9	Ireland	266.5
Czech Republic	274.0	France	262.1
Slovak Republic	273.8	Spain	251.8
Canada	273.5	Italy	250.5
England (UK)	**272.6**	-	-

Average score: 272.8

Within the UK perspective, Skills for Life Survey 2011, reported that 56.6% of the adult population in England aged 16-65 years achieved a level 2 or above score in literacy. 28.5% of the respondents, achieved literacy level 1 while the rest of the respondents (14.9%) achieved entry level 3 and below. The overall distribution, of numeracy skills data, shows that 76% of respondents achieved an entry level 3 scores or above in numeracy with 24% achieved an entry level 2 score or below (Skills for Life Survey, 2012).

However, in showing the prevalence of health literacy, there is limited research evidence available and systematic reviews are needed around the world. Rudd (2007) reported 46% of the adult population in the USA has restricted health literacy proficiencies. In Canada, 60% of the adult population reported the lack of skills to manage their health literacy needs (CCL, 2008). The European Health Literacy Survey revealed that 35% of the participants have problematic health literacy (Sorensen et al., 2012). In England, people have low functional health literacy, as 43% of working age adults (16-65 years) were below the text only competency. This figure even goes higher to 61% when it includes numeracy skills (Rowland, Protheroe, Winkley, Richardson, Seed & Rudd, 2015).

These levels of literacy, and particularly health literacy, contribute significantly to the disease burden and thus reinforce health and economic inequalities. A significant part of the population, even in the richest countries, is ill-equipped to deal with a rapidly changing society (Kickbusch, 2001).

Although the health literacy level is a concern for all, people with certain characteristics such as ethnicity, age, gender, and disability may have a higher risk of inadequate health literacy. These social determinants are not well covered in the research of health literacy. Zamora and Clingerman (2011) describe low level of health literacy in people 65 years and above that can be a barrier to obtaining and adhering to medicines. A reduced cognitive functioning, vision and hearing can impact on the health literacy level of the older person (Gellad, Grenard & Marcum, 2011). Lower level of health literacy has been recorded in people with long-term medical conditions such as: diabetes (Al Sayah, Majumdar, Williams, Robertson, Johnson, 2013); heart disease (Baker et al., 2011); chronic musculoskeletal conditions (Lowe et al., 2012; Loke, Hinz, Wang, Rowlands, Scott & Salter, 2012); and chronic kidney disease (Fraser, Roderick, Casey, Taal, Yuen & Nutbeam, 2013).

People with limited health literacy find it difficult to manage long term conditions on a daily basis (WHO, 2013) and less able to prevent progression of long term conditions (Oldach & Katz, 2014). People with mental health problems and learning disabilities are also at higher risk of limited health literacy (Public Health Wales, 2010). US-based systematic reviews also mentioned that people from ethnic minority groups are at higher risk of low health literacy (Berkman, Sheridan, Donahue, Halpern & Crotty, 2011; Weekes, 2012). The role of ethnicity is less explored in determining health literacy levels and earlier research exploring health literacy, in an ethnic community in the UK, health literacy and ethnicity described in detail in the section 2.6.2 (p. 55). Health literacy in

relation to wider health outcomes and specifically within self-management perspective (i.e. chronic conditions) is discussed in the following section.

2.5.2   Health literacy and health outcomes

In 1990 evidence began to emerge about the prevalence of low literacy in health care settings and its influence on health outcomes (AMA, 1999). Health literacy has been studied in healthcare settings (Scudder, 2006) and research has shown the association between health literacy and better health outcomes (Gazmararian, Williams, Peel & Baker, 2003; Sudor, Landefeld, Perez-Stable, Bibbins-Domingo, Williams & Schillinger, 2009; von Wagner, Knight, Steptoe & Wardle, 2007; Lee, Arozullah & Cho, 2004; DeWalt et al., 2004; Paasche-orlow & Wolf, 2007).

As discussed earlier the majority of the research has been conducted in the USA by considering health literacy as a risk. Association between health literacy skills and health outcomes most likely represent two related underlying processes. Firstly, low health literacy may have a direct, negative effect on health. This effect may be particularly important for conditions that require substantial and complex self-care on the part of the patients, because of the barriers to accessing and using health information, particularly written information. Second, low health literacy may be a marker for other conditions, such as poverty and lack of access to healthcare, which lead to poor health (Pignone, DeWalt, Sheridan, Berkman & Lohr, 2005).

Adequate health literacy has been associated with healthy lifestyles that can prevent poor health. In 2007, von Wanger, Knight, Steptoe and Wardle investigated functional health literacy and health-related behaviours in British adults. High level of health literacy was associated with healthy behaviours i.e. consumption of fruits and vegetables and non-smoking habits. Health literacy affects individuals across the spectrum of health care from

prevention of ill health to screening, history taking, explaining diagnosis and treatment. People with low health literacy skills have difficulties in understanding the frequency and timing of the dosage and neglect follow-up treatment plans as well. Health literacy can impact on the health outcomes through different paths: knowledge, prevention and management of chronic disease (Young, 2004). Having presented health literacy in the wider context of health outcomes, next section is focused on the implications of health literacy to self-management of the chronic medical conditions.

2.5.3   Implications for self-management

In the UK, 17.5 million adults may be living with chronic disease, and by 2030, it is estimated that the incidence of chronic conditions in over 65 years will more than double (DoH, 2013). In the England alone, 14% of those aged under 40 have one chronic condition; 58% of those aged 60 and over report having one chronic condition; and 25% of those over 60 have two or more chronic conditions (DoH, 2012). Self-management of the chronic conditions is a key policy issue in the UK. The 1999 White Paper (Saving Lives: Our Healthier Nation) acknowledged that people with a long-term medical condition are skilled at recognising the signs and symptoms when their condition is getting worse (DoH, 1999). Subsequently, the NHS plan set out a vision in which the NHS will become a resource (equipped with evidence based research, and frameworks) that people can utilise in the self-management of the chronic conditions (DoH, 2000). The Department of Health (2013) also acknowledged that good chronic disease management could make a real difference, helping to prevent crises and deterioration, and enabling people living with chronic conditions to attain the best possible quality of life (DoH, 2013).

Although in the past 20 years there have been dramatic advances in the management of chronic disease, the complexity of the health care system, puts more

responsibility on the patients to manage their disease so that it is hard for the people with low literacy skills (Gazmararian et al., 2003). Mackey, Doody, Werner and Fullen (2016) conducted a review to understand the role of health literacy in chronic disease management. They suggest that health literacy may affect behaviours necessary for the development of self-management skills. There is a recognised association between low health literacy and lower disease-related knowledge in people living with asthma that effect on the effective management of their condition (Federman, Wisnivesky, Wolf, Leventhal & Halm, 2010). Successful chronic disease management requires ongoing patient-provider collaboration, and health literacy is foundational to this reciprocal partnership. Patients need skills to process and act on the health information; providers need skills and resources to deliver that information in ways that support comprehension and uptake (Coleman, 2011).

Patients with chronic disease have been found to be at increased risk for misunderstanding their diagnosis, treatment regimens, and instruction for self-management (Berkman et al., 2011; Schillinger, 2001; Chiarelli, 2006 The Department of Health (2013) contends that although the complexity and challenge of managing chronic conditions are complex however the system of managing chronic care can be simple. Different interventions for chronic conditions can be used with different degrees of complexity that can add different outcomes (DoH, 2013).). Self-management skills that are health literacy sensitive, can improve the health outcomes of people living with chronic conditions. Consideration and development of health literate people and health care settings can also be helpful to increase the needed access and utility of the healthcare services to promote and maintain health.

2.5.4   Implications for access and use of healthcare services

Health literacy can have implications for different aspects of health and healthcare processes. It can be important to the access and utility of healthcare services, for information, patient-provider interaction and shared decision making process in the healthcare settings.

Health literacy has been associated with the use (or not) of primary care and prevention services (Scott, Gazmararian, Williams & Baker, 2002). von Wagner, Steptoe, Wolf and Wardle (2009) developed a model to illustrate to pathways between health literacy and screening use, shared decision making and medication adherence (Figure 2.8, p. 53). In this model, they suggest a number of motivational barriers to the use of prevention services. This model shows the motivational pathway that describes the interaction between health literacy and established social cognition variables (e.g. health-related knowledge, attitudes, or beliefs, and the decisions to use primary prevention services). The health literacy abilities of the individuals (i.e. reading and comprehension of written health material) play an important role in the use of these services (von Wagner, Steptoe, Wolf & Wardle, 2009).

Further more people with low health literacy skills may not be able to take benefit of the educational campaigns for health promotion and disease prevention, and their decision related to the use of health services is mainly influenced by their personal experiences rather than up-to-date health education advice (von Wagner et al., 2009).

Differences in literacy and numeracy skills lead to marked variation in an individual's ability to obtain relevant health information and their capability to apply this information in their interaction with health professionals and services (DeWalt et al., 2004). Lack of knowledge about preventive care is also associated with negative beliefs

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about these services (Gordon, Hampson, Capell & Madhok, 2002). Further personal experience, information gathered from lay networks may also be associated with fatalism and negative beliefs associated with the efficacy of screening. It can be suggested that health literacy can play an important role in determining the use of preventive services (Davis, Dolan, Ferreira, Tomori, Green & Sipler et al., 2001).

Another skill that has often been cited in conjunction with health literacy is navigation. Healthcare institutions are complex structures and busy environments that require having sophisticated navigation skills (Rudd, Soricone, Santos & Zobel, 2005). Paasche-Orlow and Wolf (2007) also signify the role of navigation skills, which are needed to go from one place to another to pursue the health care. Although there is limited evidence available to suggest the association between health literacy and the navigation of health services, people with low health literacy find difficult to find their ways in health care facilities. It is also unclear as to what extent navigation may refer more broadly to tasks including the navigation of media, use of the internet and the ability to choose appropriate health care services.

There are some of the other factors that also demonstrate the role of the level of health literacy of the individuals and their access and use of healthcare services. Limited health literacy has been associated with distrust towards providers, pessimism about treatment and a worse assessment of the quality of care (Kalichman & Rompa, 2000; Mancuso & Rincon, 2006). People with limited health literacy skills find it hard to complete the complex forms, struggle to interact with the healthcare professionals and have difficulties in following medication instructions (The Joint Commission, 2007). In the face of these complex tasks, people with limited health literacy skills prefer not to use health care services to avoid the shame and embarrassment when asking for help to fulfil any of these tasks (Baker et al., 1996).

National Health Services (NHS) in the UK have inroduced initiatives to increase the patient's choice; patients are offered a number of specialist care options available online, so they can book their preferred services and booking time for an appointment. Although no research has been conducted to investigate its efficacy, it is expected that such initiatives will not benefit to people with low literacy skills and may not produce expected results (Protheroe, Nutbeam & Rowlands, 2009).

Patient-provider communication plays a key role in patient health, knowledge, decision-making and motivation. Communication is also critical for appropriate diagnosis, treatment and management of the disease (Schillinger, Potter & Heisler, 2003). Effective and constructive communication is highly significant in ensuring positive health outcomes (Nouri & Rudd, 2015) and can improve adherence to medical recommendations (Cohan, Bonito, Eicheldinger, Manski, Edwards & Khanna, 2011). Cultural, language and communication barriers collectively or independently have the great potential to lead to mutual misunderstanding between patients and their healthcare providers (The Joint Commission, 2007).

A lack of awareness among health care providers about the health literacy level of the patients can act as a barrier to effective communication in healthcare settings (Paasche-Orlow & Wolf, 2007). Many patients with reading problems may feel ashamed and hide their inability to read. Shame is such a deeply harboured emotion that plays an important role in understanding how patient with different health literacy levels interact with healthcare providers (Parikh, Parker, Nurss, Baker & Williams, 1996). The sense of shame can also be aggravated within the healthcare context when health care providers get frustrated by the failure of following the signs and filling out medical forms by the people with low health literacy skills (Baker et al., 1996).

In the causal model, Paasche-Orlow and Wolf (Figure 2.4, p. 28) also mention how different factors can effect effective communication between health care providers and the patients. Patients less knowledgeable about the severity of the disease can influence the activation of the patients in asking questions about their condition. This can leave the patient more passive and may complicate the patient-provider communication. Patients' misunderstanding of physician communication, disease management, prevention and problems of informed consent all send clear messages to the health care system that there is need to deal appropriately according to the needs of the patients with different health literacy needs (AMA, 1999).

Shared decision making is an example of health action that is dependent upon patient-provider interaction and can be influenced by the health literacy level of the patient (Edward, 2011). Health information is an important resource to support understanding and engagement in the shared-decision making processes in the management of health conditions. Ishikawa and Yano (2008) suggest that the communication skills of patients (i.e. information seeking, information verifying and information provision) are indicators of active participation in medical care and are closely related to the Nutbeam definition of communicative health literacy (Nutbeam, 2000). They further suggest that a patient's level of confidence in participating in medical care can reflect the level of critical health literacy skills.

People with low health literacy have lower participation in shared-decision making processes (Mancuso & Rincon, 2006) that increase their dependency on family members or healthcare providers as final decision makers for them (Collins, Crowley, Karlawish & Casarett, 2004; Barragan, Hicks, Williams, Franco-Paredes, Duffus & Rio, 2005). Mancuso and Rincon (2006) study of health literacy and the desire of individuals to participate in shared-decision making process suggested that patients with lower health

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literacy skills were less likely to participate in decisions about their care. Authors thus suggest two possible explanations for the lack of participation in decision-making process. Firstly, the patients with lower health literacy skills may perceive a gap in their medical care due to limited communication with the healthcare providers and less understanding of the information received. Secondly, patients with low health literacy may want to have information but are reluctant to be part of the shared process because limited health literacy skills hinder in understanding health care information and they do not feel confident to be part of the care process. Another study with diabetic patients also showed that low health literacy was associated with less desire to participate in the medical decision process and less diabetes-related knowledge (DeWalt, Boone & Pignone, 2007).

As mentioned earlier von Wagner et al.'s (2009) model suggests a number of motivational barriers to shared decision making (Figure 2.8, p.53). The barriers involve technical terms, complex ideas, multiple options and the need to differentially weight the relative value of unfamiliar choices. Patients with limited health literacy skills may cope with this situation by using maladaptive strategies to avoid the burden of decision making. Lower health literacy also predisposes towards the use of easily understood factors rather than more analytical information process in the health domain (von Wagner et al., 2009).

Figure 2.8: Pathways between health literacy and screening use, shared decision making and medication adherence (von Wagner et al., 2009. p. 866).

Health Literacy

Motivational Phase

Knowledge
Knowledge of health services
Knowledge of abstract and unfamiliar concepts (e.g. screening, risk and probability)
Disease-specific and treatment knowledge (HIV, -RNA suppression, how to avoid symptoms triggers)

Attitudes
Negative belief and attitudes
Preferences for emotional rather than analytical information processing

System factors
(Health-care costs, accessibility of health information, provider communication skills)

Volitional phase or action control

Task specific skills
Information processing and navigation skills (attention, memory)
Decision making skills (Structuring choices, weighing up benefits and barriers)
Cognitive and illness management skills (sensory abilities, working memory, ability to organize cues to action and implementation plans)

Access and use of primary care prevention services

Typical examples would be to follow recommendations for screening

Shared decision-making

Relevant contexts are choice bewteen different health options (e.g. choice of test or treatment)

Adherence to medication

Relevant contexts are management of chronic illness (e.g. HIV-AIDS, asthma, CHD)

2.5.5   Summary

There is plenty of research evidence available that suggests an association between levels of health literacy and health outcomes. This highlights the need to assess the prevalence of health literacy, the majority of data available about the prevalence of health literacy is within the context of the USA, although there is subsequent data available in other developed countries such as Canada, Australia, New Zealand and England indicating that health literacy is a concern for these countries. Health literacy is associated with equality in modern healthcare in the developed countries too. Health literacy effects in many ways the individual in the healthcare context, e.g. when reading a prescription, filling out a consent form, following a hospital map, booking an appointment and communicating with the healthcare professionals (Scudder, 2006). It can effect the utilisation of health-related knowledge and information that can be used to prevent the disease or as part of the management of the medical condition.

The health literacy of an individual can have an effect from many different perspectives that can impact on the utility of health information and services to maintain good health. People with limited health literacy may face difficulties in accessing and using the correct healthcare services (Scott et al., 2002) they may under use the preventive services (Von Wagner et al., 2009) which can lead to marked variations in the health status of the people with limited health literacy skills (DeWalt et al., 2004). Further, it can effect the patient-provider interaction (Persell, Osborn, Richard, Skripkauskas & wolf, 2007) and limit the capacity of autonomy in the shared decisions making process (Mancuso & Rincon, 2006). There is a need to consider the individual characteristics with the system factors that should be considered in improving access and utility of the health care services for the entire population in the society.

2.6 Health inequalities and health literacy

This section discusses the health literacy from the perspective of health inequalities. Ethnicity can be one of the social determinants for health inequalities. Limited health literacy is also higher in people belonging to ethnic groups, so that is also discussed in this section.

2.6.1 Health inequalities

Health inequalities have been the subject of both research and policy attention and tackling inequalities in health is now an overarching aim of all the public health policy throughout the world (Judge, Platt, Costongs & Jurczak, 2006). In the last three decades, there are a number of high profile reports that have demonstrated the link between social and wider determinants and health inequalities in the UK e.g. Black Report, 1980; Acheson, 1998; The Marmot Review, 2010. In 1980, the Black Report determined that the main cause of health inequalities was economic inequality. It was recommended that fair distribution of resources could be effective in tackling health inequalities (Black, 1980). In 1998, Donald Acheson conducted an inquiry into inequalities in health, and he recommended giving priority to the health of the families and further suggested reducing income inequalities and improving living conditions of the poor household (Acheson, 1998).

In 2008, the WHO published a report on the social determinants of health (CSDH, 2008) and in the same year the Scottish Government also published its *Equally Well Report*, emphasising the evidence of links between health inequalities and socioeconomic deprivation (The Scottish Government, 2008). In the UK, a report *(Fair Society, Healthy Lives)* was published in 2010 that captivated the attention of politicians across the political spectrum. In this report, it was stressed that tackling health inequalities is a matter of social

justice with real economic benefits and savings, and the call for action to tackle the social gradient in health outcomes was raised (Marmot, 2010). In the same year, the UK parliament committee of public accounts confirmed that the gap in life expectancy between people in deprived areas and the general population has continued to widen (House of Commons, 2010). Although the NHS spending 4% of their budget in tackling the health inequalities while its contribution in reducing health inequalities is still not clear (RCN, 2012).

All the evidence so far suggests that the socio-economic deprivation and health inequalities go together. In terms of a cluster of competing and complementary explanations for inequalities in health, ethnic background is considered one of the strong indicators. Ethnic minority groups are discriminated against, and recognise themselves as disadvantaged. This not only occurs in the form of a failure to achieve the full potential of economic success but also in everyday exclusion from the element of the mainstream dominating society (Nazroo, 1998). Ethnicity in relation to health inequalities is described below.

2.6.2 Ethnicity and health inequalities

Health status and health outcomes amongst racial and ethnic groups are often significantly different from the people who registered as privileged groups or than population averages (Nazroo, 1997,1998; Public Health England, 2015; RCN, 2012). Non-indigenous groups endure racial discrimination in many countries and often have health indicators inferior to the indigenous population. In the USA, life expectancy for African Americans is lower than white Americans (Oliver, 2008), while in Australia, the average life expectancy of the Australian born population is higher than the overseas-born population (AIHW, 2002). The WHO (2005) reported inequalities in health between ethnic groups in developed countries.

For example, in New Zealand, Maori and Pacific's people have worse health outcomes than New Zealanders. In the USA and the UK, the immigrant population has the poorest health while Norway is particularly concerned about the social and health inequalities among the non-western immigrants (WHO, 2005).

Inequalities between migrants and indigenous population exist in Europe in terms of health status and access to health services (Benzeval & Meth, 2002). People from ethnic minorities may have higher risk of developing communicable diseases (i.e. TB, HIV/AIDS, hepatitis), non-communicable diseases (i.e. Cardiovascular diseases, diabetes, hypertension) and mental health problems due to the combination of the socioeconomic and environmental conditions as result of the migration process, and as an ethnic minority status in the host countries (Commission of the European Communities, 2009).

Racial discrimination associated with disadvantaged social position (i.e. low income, poor education, poor housing, etc.) can have a cumulative effect on the health of the people of ethnic minorities (WHO, 2010). There is considerable debate about the interplay between biological, genetic and social factors for the health of people belonging to ethnic minorities. Unequal social relations (characterised by discrimination and exclusion) are thought to have profound consequences for the economic and social well-being of ethnic groups that may lead to inequalities in health in the future. Racial discrimination may confine the people of ethnic minority workers to a certain type of low paid jobs and low-status occupations that may also have an impact on the health of these individuals (Cooper, Hill & Powe, 2002).

The publication of the Black Report (1980) revealed inequalities in health in the UK within different groups of social class regarding the mortality rate. Since then, considerable research evidence has emerged about health inequalities that exist and

growing ever wider between socioeconomic groups, geographic areas, and men and women and among members of different ethnic minority groups (DoH, 2002).The diversity of migrants in the UK, regarding origin, ethnicity, socioeconomic circumstances, religion, legal status and length of residence has a significant implication for their health status and needs, and entitlement and access to healthcare (Jayaweera & Quigley, 2010).

In the UK, provision of health care for ethnic minorities has become a particularly important area of debate, and a series of high-profile government initiatives have sought to achieve a better understanding of health inequalities and how it can be reduced (Sproston & Mindell, 2006; DoH, 2002). There are a number of factors that are associated with ethnic inequalities in health care; health-related behaviours (diet, smoking, drinking, exercise habits), genetic predisposition, material environment and resources, and further differences associated with direct and indirect consequences of racism can all have an effect on the health status of those in ethnic communities (Evandrou, 2000). The real challenge is to improve health outcomes by improving equal access and utility (for equal needs) of the healthcare services in needed.

2.6.3 Implications for health literacy

A disparity in health and health care access is an alarming factor. Low socioeconomic status, comorbidities, educational attainment, ethnicity, sex, and poor access to the health care system have an association with health literacy (Public Health England, 2015; Public Health Wales, 2010). It signifies the importance of health literacy in health promotion and reducing health disparities in society (Sudore et al., 2006; Von Wagner et al., 2007; Paasche-Orlow, Parker, Gazmararian, Neilsen-Bohlman & Rudd, 2005). The level of health literacy is a strong contributor for producing inequalities in society and reducing the gap in the level of health literacy can reduce some of the inequalities in European societies

in terms of life expectancy, outcomes of care, and the mortality rate (Kickbusch et al., 2006). Poor health literacy not only effects the health of an individual but it also creates social and cultural consequences significantly contributes to poor health, and can be a reason of social inequalities in society (Kickbusch & Maag, 2008).

The real challenge is to ensure that actions make a difference regarding people's health and wellbeing. Ensuring equal access to health care (for equal needs) would appear to be the most attainable equality goal and improving access to health services by the Black and Minority Ethnic (BAME) groups will reduce the gap between these groups and the white population (CSDH, 2007). Evidence shows that people from ethnic and migrant communities have low health literacy and poor health outcomes than the general population (WHO, 2013; Berkman et al., 2011). These marked variations in health literacy level and health outcomes can be attributed to the difficulties faced by ethnic communities that hinder their effective access and utility of the healthcare information and services (Berkman, et al., 2011; Kreps & Sparks, 2008). According to Szczepura (2005) language can be a major barrier in the utilisation of healthcare services among these people. The Office for National Statistics found that 41% of the people who speak English as a second language receives no interpretation support over their visit to health care professionals (Office of National Statistics, 2005). These limitations can impact on the effective utility of the information and services that can lead to poor health outcomes (Saha & Kanaya, 2014).

In the UK the goal to provide effective health care services is complicated by the reduced access to services by black and minority ethnic groups (BMEs). There are differences in socio, demographic and economic characteristics of the BMEs and the white population that highlights the needs of distinct health care needs for each group along with the capacity to access healthcare services (Lee, Sayed & Bellis, n.d). In this debate of increasing access to health care services, health literacy can play a vital role in reducing

health inequalities in ethnic minority groups (Public Health England, 2015). Wang, Li, Li, Xu, Kane and Meng (2013) presented the theoretical models that link health literacy to health inequalities. It was argued that low level of health literacy decreased a person's accessibility and use of medical care because individuals with low health literacy may have difficulty navigating the health care system. These difficulties can be a reason for stress that can make self-management of illnesses worse and also decrease self-efficacy of individuals (Wang et al., 2013).

Public Health England (2015) presented a document about target the local actions to improve health literacy and reduce health inequalities. Within this perspective, health literacy is considered an empowerment tool to reduce the health inequalities in the vulnerable groups. It was also acknowledged that solely focusing on the most vulnerable and disadvantaged groups will not be sufficient to reduce health disparities. In this regard, there is a need to have health literacy initiatives and actions more universally distributed across the population but with more focus on the groups who might be more vulnerable and disadvantaged. This was called "proportionate universalism" with more focus on the people who are at higher risk. It stressed the importance of having actions at the local level to improve the health literacy of disadvantaged or vulnerable groups embedded within a broader strategy: a) improve the health literacy of health and social care systems, and b) address the conditions in which people born, grow, live, work and age (Public Health England, 2015). The figure of having targeted local actions to improve health literacy and reducing health inequalities is presented in Figure 2.9 on the following page (p. 61).

Figure 2.9: Local actions to improve health literacy and reduce health inequalities (Public Health England, 2015, p.8)
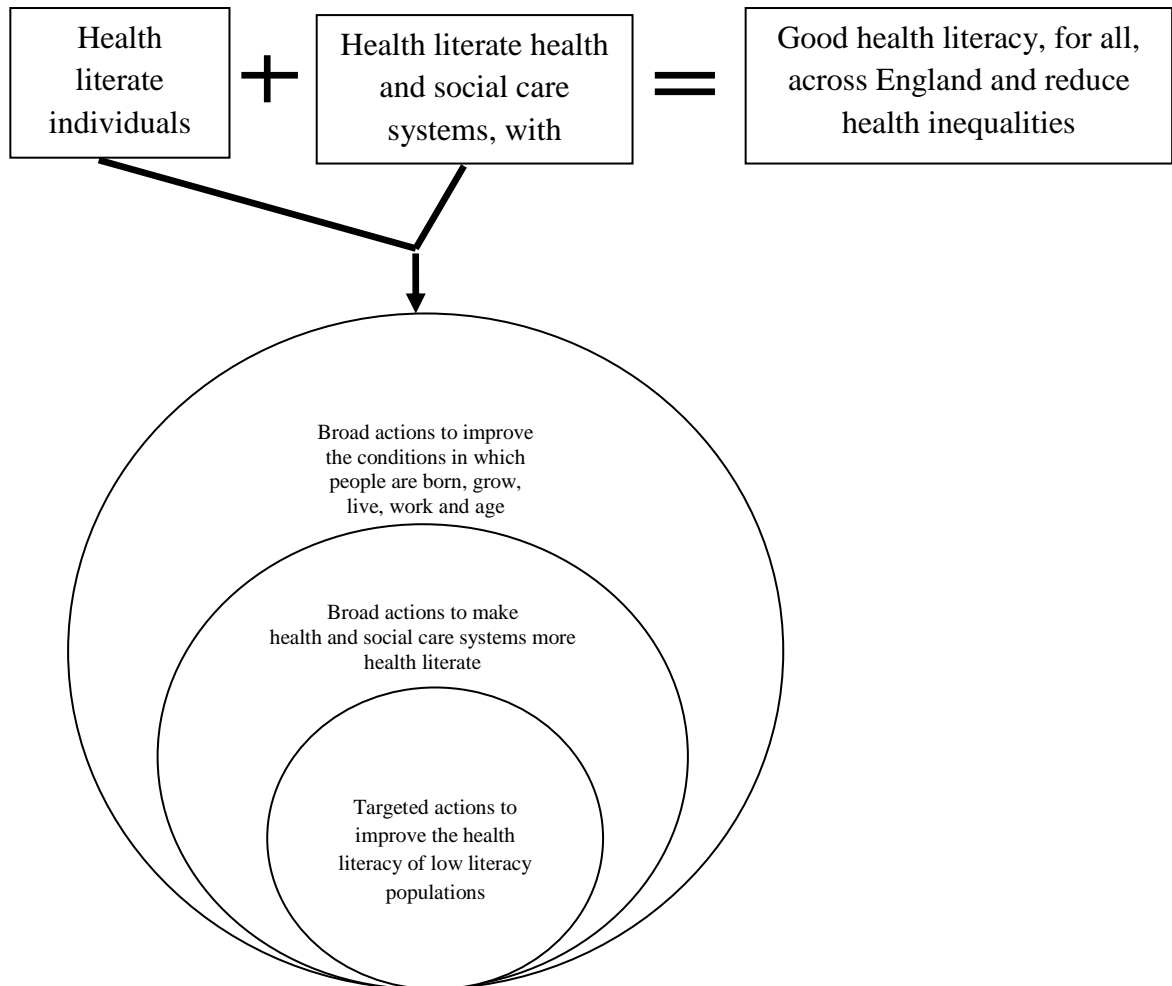
The idea of improving health literacy to improve health and reduce health disparities is growing in the UK; different initiatives have been taken in this regard. The development of the Health Literacy UK group and the debriefing presented by Patient Information Forum (2013), the Community Health and Learning Foundation (Lamb & Berry, 2014), Association for Young People's Health (Hagell, 2015) all sought to draw attention towards the priority actions in improving health literacy with the aim to reduce health inequalities. However, there is still research evidence needed to assess the health

literacy initiatives among disadvantaged individuals/communities and to understand the role of health literacy in reducing health inequalities.

In developing strategies to improve health literacy, it is important to consider the people who might be in the disadvantaged position, for example, older people, people with learning disabilities and people from ethnic minority groups. According to the Equality and Human Rights Commission (2014) this can be achieved through minimising the barriers and take steps to meet the specific needs of the people who share certain characteristics that may be different from other people.

As discussed earlier the concept of health literacy is very sensitive to context and culture, and its meanings can differ across cultures/ countries or racial/ethnic groups (Baker, 2006; Saha, 2006). Since the level of health literacy may be affected by the culturally shaped models of illness and health, it is important to expand the understanding of health literacy to include the cultural strengths that patients bring to disease self-management (Shaw, Armin, Torres, Orzech & Vivian, 2012).

In current research, the aim to explore health literacy in South Asians living with diabetes fits well with the framework presented by Public Health England (2015) that also has the focus to reduce health inequalities through improved health literacy. This research holds a "pragmatic approach" that considers truth to be ''what works'' (Tashakkori & Teddlie, 1998) and the adopted framework in this research is simple to follow as compared to other frameworks, which have a lot of boxes and arrows to show the connections and complexities between different dimensions and aspects of health literacy.

It has been mentioned earlier that majority of the work in the field of health literacy has been done from the risk perspective so does the frameworks reflect that approach to describe health literacy as a risk too. However, the Public Health England

(2015) framework holds the asset approach that describes health literacy as an asset to empower the people and communities to have improved health status. Although few of the models are describing public health approach towards health literacy thus the notion of developing community resources as previously described in the definition of health literacy (WHO, 2015) is not a well-documented approach in the frameworks and models presented in Section 2.3 (p. 23).

The adopted model in current research which takes into account how the wider social determinants and community resources needs to be considered in developing an approach to reduce health inequalities through improved health literacy. Social problems like poverty and inequalities require a pluralistic approach. Hence the focus is in not on the individual problem, but rather understanding how the problem arises within any particular setting (Lawthom, 2011). Overall, considering the pragmatic approach in current research also acknowledges the fact of making a real difference in the lives of the people to have better health and good quality of life. This can be achieved through research evidence that contributes to developing local actions to improve health literacy with the aim to reduce health inequalities.

2.6.4   Summary

In the last three decades, several high profile reports had demonstrated the link between social and wider determinants and health inequalities around the world and in the UK. These inequalities have roots in unequal distribution of socioeconomic resources that stressed tackling health inequalities as a matter of social justice. The evidence so far suggests that socioeconomic deprivation and health inequalities go together and people belonging to ethnic minorities are considered to be at a disadvantaged position. Ethnic minorities are at higher risk of developing communicable and non-communicable disease

due to lack of access to health care resources (WHO, 2013; Berkman et al., 2011). In the

UK, there is a great diversity regarding ethnic minorities, and an over-arching aim of the

Department of Health in England is to provide equal health care services to ethnic

minorities to reduce health disparities. Health literacy as the capacity to help individuals to

improve access and use healthcare services and information which can be an important

factor to reduce the health disparities in ethnic communities.

3   South Asians, Diabetes and Health Literacy

3.1   Introduction

Over the past half century, there have been significant changes to the world population. Economic changes and demand for skilled labour with increasing industrialisation have resulted in the migration of people from poorer and developing countries to developed countries (Barnett et al., 2006). Migration to the UK and Europe occurred in two phases: The first wave of migration occurred after the Second World War, when countries like France and the UK recruit people from their ex-colonies to meet the increased labour demands (Barnett et al., 2006). A further wave of migration occurred in the 1960s and 1970s, due to political turmoil in East Africa and more recently technological progress and skilled labour resulted into the migration towards a different part of the world i.e. Australia, USA and Canada (Bellary, 2010). While population migration from South Asian countries (India, Pakistan and Bangladesh) has occurred to many parts of the world but in the UK alone over 2 million South Asians have settled representing 4% of the total population (Office of National Statistics, 2011).

3.2   South Asian ethnicity

The term South Asians broadly refer to the people belonging to India, Pakistan and Bangladesh origin; however people from Nepal and Sri Lanka also included in this ethnic group. In the UK, people belonging to the South Asian community make up the second largest ethnic group after white populations (Khunti, Kumar & Brodie, 2009). South Asian ethnic minorities may have diversity within its sub-groups, but at the same time, they share many socio-cultural factors and particularly higher susceptibility for diabetes and

cardiovascular disease. So it is important to treat each community individually considering their cultural features such as customs, religion, food, lifestyle and languages (Barnett et al., 2006).

There is considerable variation in the reported health of the ethnic minorities in the UK (Nazroo, 1997; Rudat, 1994). People of South Asian descent have greater health disparities as compared to the white British people in the UK. However, there are differences in subgroups of South Asians and their health status. Indians have advantage health conditions not so dissimilar from the white people while people from Pakistani and Bangladeshi community substantially reported higher morbidity. Women of Bangladeshi and Pakistani origin reported highest rates of poor health and long-term illness (Health Survey England, 2004). These differences within South Asian sub-groups also can be observed in their socio-economical position in the society. Indians have advantageous position while Pakistani and Bangladeshi emerged as the poorest and deprived groups across a range of social indicators (Modood, 1997).

In general, people belonging to South Asian origin are more likely to report bad health than the white population (Randhawa, 2007) and diabetes is a particular matter of concern in the South Asian community (Diabetes UK, 2012). Pakistani and Bangladeshi men and women are more likely than the general population to have raised waist to hip ratio and raised circumference (Randhawa, 2007) a high-risk factor in developing diabetes (NICE, 2012; Diabetes UK, 2012). Indian, Pakistani and Bangladeshi men and women are less likely than the general population to meet the physical activity recommendations (of at least thirty minutes of moderate to vigorous exercise on at least five days a week) (Diabetes UK, 2012).

A further complication associated with diabetes in the South Asian community is diabetes nephropathy (a kidney disease) that is a major cause of end-stage renal failure

(ESRF) in South Asians in England. Within a broader perspective of the UK, South Asians with diabetes are up to ten times more at risk of developing ESRF compared to the white population (Lightstone, 2001) and calculated the cost for running renal dialysis is around £22,355 per person (NICE, 2011). The higher risk of developing diabetes and its associated complications highlighted the need to study diabetes within the perspective of this community. Although there is substantial research available about diabetes within the South Asian population, health literacy as an asset to develop the capacities at an individual level and within community resources to improve diabetes management is less explored in this community.

3.3 Diabetes

Diabetes has emerged as a major health problem worldwide (WHO, 2016), with serious health related and socioeconomic impact on individuals and populations alike (Ali, Weber & Narayan, 2010). Diabetes is a chronic medical condition that is considered incurable and treatment of this condition imposes severe constraints on the lives of the people who are suffering from this condition. The treatment of diabetes and quality of life of people while living with this condition has much improved after the discovery of insulin in 1922. However, it is considered that the complexity of the condition and much of the responsibility for its day to day management lies with the diabetic person (Kelleher, 1988).

Diabetes mellitus (DM) is defined as a disorder of metabolism in which a relative or absolute deficiency of insulin leads to hyperglycemia with or without glycosuria (Ghosh & Collier, 2012). Disturbances of intermediate metabolism, the alterations in protein and fat metabolism and uncertain relationships between diabetes and its various degenerative complications, all demonstrate the complexity of this disorder (Drury, 1979). Diabetes is a disorder in which the mechanism for converting glucose to energy no longer function

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properly, and it causes a high level of blood glucose in the body giving rise to many other symptoms. If the level of blood glucose remains high for several years that can have a devastating effect on many parts of the body, so the treatment aim is not only to reverse the symptoms but also to prevent any serious problem developing in later life (Day, 2001).

Diabetes is considered one of the major cause of morbidity and premature mortality due to the complications like; cardiovascular disease, blindness, renal failure, amputation, and stroke. However, with early established good control of hyperglycemia that continues for life long, an individual with diabetes can enjoy a good quality of life and can reduce the risk of developing complications in later life (Holt & Kumar, 2015). WHO has been defined diabetes:

> "The term diabetes mellitus describes a metabolic disorder of
> multiple aetiology characterised by chronic hyperglycemia with
> disturbances of carbohydrate, fat and protein metabolism resulting
> from defects in insulin secretion, insulin action, or both" (WHO,
> 1999, p. 2).

The main symptoms of diabetes are:

- Thirst or dry mouth
- Passing large amount of urine
- Weight loss
- Tiredness
- Itching of the genital organs
- Blurring of vision

    Normally, the amount of glucose level in the body is very carefully controlled.

Glucose is obtained from the food, either from sweet things or starchy food (carbohydrates), such as potatoes and bread. Glucose can also be made through the

breaking down of the body stores of starch in the liver, but this happens when several

meals are missed, in the case of injuries or being unwell (Forouhi, Hall & McKeigue,

2005). The use of glucose to provide energy requires the presence of a chemical that is

called insulin. Insulin is released into the blood when blood glucose rises after the meal

and plays a function to bring glucose to the normal level (Ghosh & Collier, 2012). Less

insulin is produced when the glucose level falls e.g. during exercise. Insulin plays an

important role in maintaining the correct level of blood glucose level. In the case when

there is a shortage of insulin, or if the available insulin does not function properly, then the

blood glucose rises and diabetes results (Day, 2001). Classification of diabetes is discussed

in the next section.

3.3.1   Classification of diabetes

In 1980, the WHO published the first classification of diabetes that was revised in 1985.

Both 1980 and 1985 classifications included two clinical classes and two statistical risk

classes. In 1980 classification, two major classes of diabetes introduced and named 'type

1' diabetes or 'IDDM' and 'type 2 diabetes' or 'NIDDM'. In 1985, the two terms type 1

and type 2 were omitted, and a new term 'Malnutrition- related Diabetes Mellitus'

(MRDM) was introduced. Impaired glucose tolerance (IGT) was also introduced as a high-

risk class along with gestational diabetes. Based on the increasing knowledge in 1999, a

new classification of diabetes proposed by the collaboration of WHO and American

Diabetes Association (ADA). Diabetes is classified into four groups-types1 diabetes, type

2 diabetes, other specific types and gestational diabetes. In 2006, the WHO again revisited

the classification but no further modification was introduced, IGT was removed from the

diabetes classification and is considered a risk state (that increase the chance to develop

diabetes). Impaired fasting glycemia (IFG) was also introduced as another risk state for diabetes (George & Alberti, 2010).

3.3.1.1 Type 1 diabetes

Type 1 diabetes mellitus (IDDM) is characterised by autoimmune beta cell destruction usually leading to absolute insulin deficiency. The cause of the destruction of insulin-producing cells is not known for certain, but a combination of factors might be the cause that includes: damage to the insulin-producing cells by viral or other infection or maybe there is an abnormal reaction of the body to the insulin producing cells (Day, 2001). This type of diabetes may have an acute onset and symptoms may progress in days or weeks (ADA, 2015). The classical symptoms of type 1 diabetes include thirst, polyuria, and ultimately coma is sudden. This type of diabetes is more common in Caucasian populations and to peak incident of developing this condition is around the age of 10 to 13 years of age (Kelleher, 1988). This type is developed in younger people, but it may occur in older people as well. Both male and female may have equal chances of developing it. There is some tendency of running this type of diabetes in the families, but the condition is far from being purely inherited (Day, 2001).

3.3.1.2 Type 2 diabetes

Type 2 diabetes is usually diagnosed around middle age and the prevalence increases with age. However early onset of type 2 diabetes in some groups of the population (i.e. South Asian) has been recorded (Diabetes UK, 2012). The symptoms include increased thirst, skin irritation, and tiredness (Kelleher, 1988). In type 2 diabetes the insulin-producing cells are still producing insulin, but that might be insufficient in quantity or not working properly. The majority of people with type 2 diabetes can be treated with diet, or by the

combination of diet and medications and in some cases there is a need to have insulin therapy to establish a good control of blood glucose levels. There is no absolute cause has been identified to date about the cause of type 2 diabetes. People who are overweight are more likely to develop this condition, and it tends to have a genetic predisposition and runs in the families (Day, 2001).

3.3.1.3   Other specific types of diabetes

Diabetes occurs as a result of specific genetic defects in insulin secretion and action and range of other conditions. These conditions of various known aetiology are grouped together. This group includes people with genetic defects of beta cell function or with genetic defects in insulin action. People with the disease of the endocrine pancreas; people with dysfunction associated with other endocrinopathies (i.e. Acromegaly, Glucagonoma); and persons with pancreatic dysfunction caused by chemicals, drugs or any infection (George & Alberti, 2010).

3.3.1.4   Gestational diabetes mellitus

Gestational diabetes mellitus (GDM) is hyperglycemia first detected during pregnancy. Individuals with type 1 and type 2 diabetes detected first during pregnancy are also classified as having gestational diabetes. Screening for GDM is taken at around 28 weeks of pregnancy. Risk factors include for GDM includes certain ethnic groups, those with previous GDM or abnormalities of glucose intolerance, age, obesity and history of previous large babies (George & Alberti, 2010).

3.3.2 Global prevalence of diabetes

Epidemiological trends indicate there has been a steady increase in developing diabetes around the world in the past few decades (Forouhi, Hall & MaCkeigh, 2005). Although an increase in type 1 and type 2 diabetes has been observed, much of this increase is attributed towards type 2 diabetes. King, Aubert and Herman (1998) predicted the global prevalence of diabetes between 1995-2025 (in adult over 20 years of age), and it was estimated that there would be a rise of 154 million people with diabetes by the year 2000. Although subsequent data shows that these figures were an underestimate about diabetes prevalence (King, Aubert & Herman, 1998; Wild, Roglic, Green, Sicree & King 2004). Global prevalence in 2000, was 171 million and it was further estimated that it is expected to double over the next two decades and will reach an alarming figure of 366 million by 2030. Recent evidence has shown even more increased statistics. Globally, an estimated 422 million adults were living with diabetes in 2014 (WHO, 2016). For the future, it was estimated that greatest relative increase would occur in the Middle Eastern Crescent, Sub-Saharan Africa, and India while the greatest absolute increase diabetes will be in India (Wild et al., 2004). The top three countries with diabetes retain their position in the higher prevalence rate of diabetes as previously that includes India, China and USA, as these are the most populous countries in the world. In the UK alone, there are four million people living with diabetes. It is estimated that in the UK, one person is diagnosed with diabetes every two minutes and another million people have diabetes but remain undiagnosed (Kntish, 2016).

The age-related prevalence of diabetes varies between developed and developing countries, as in developing countries the higher rate is in between 45-64 years while in developed countries it is higher in age 65 and above (WHO, 2016). There are no

significant differences in gender and diabetes estimates. However, the prevalence of diabetes is higher in men aged less than 60 years while in women over 60 years (Ali, Weber & Narayan, 2010; Wild et al., 2004; Koetsenruijter et al., 2015). Previously type 2 diabetes was considered the disease of the middle-aged and elderly but in recent years it is developing at a younger age and even in children. In 2000, in the UK there was the first case of childhood type 2 diabetes was reported, and now there are over 500 children have type 2 diabetes and number of new cases are rising dramatically (Kntish, 2016).

The increasing number of people with diabetes attributed towards population growth, ageing, urbanisation, nutritional and lifestyle patterns, increasing the prevalence of obese adults and children (Ali, Weber & Narayan, 2010; Wild et al., 2004; Koetsenruijter et al., 2015). Increase in the age of populations and migration of the susceptible people are considered the cause of diabetes in the developed world (Lipscomb & Hux, 2007). The projected increase in diabetes around the globe will result in the corresponding escalation of burden in the form of serious morbidity, disability, diminished life expectancy and reduced quality of life, loss of human and social capital along with individual and national income (Ali et al., 2010). Research has shown that alone in the UK, people with diabetes are twice as likely to have heart disease, three times as likely to have kidney disease and 40% of the patients on dialysis are diagnosed with type 2 diabetes (Kntish, 2016). A further complication associated with diabetes is amputation of the hand or foot.

The rising number of adults and children with diabetes and associated complication cost £10.3 billion to the NHS in the UK that is 10% of the whole NHS budget. There is a fear that due to the rising number of people with diabetes, the NHS will not be able to survive due to the rising cost of this deadly epidemic (Kntish, 2016). Increasing number of people with diabetes and its complications are likely to place a huge burden on the health care resources, and a greater emphasis on the preventive measures with rational planning

and allocation of resources is urgently required to tackle this growing problem (Wild et al., 2004).

Developing health literate individuals/communities and utility of already available community/healthcare resources can be one of the options to reduce the risk of developing diabetes (or effective management in case of living with diabetes). However it is also important to consider health and disease within cultural and social perspective of the people especially when the focus is any specific ethnic community. Next section discussed diabetes within the cultural perspective of South Asian community.

3.4   Diabetes in South Asian people

In India, there are estimated 31.7 million people living with diabetes, and that is expected rise to 79.4 million by 2030. Pakistan and Bangladesh are also listed in the top ten countries in the world having the highest prevalence of diabetes. In Pakistan, 5.2 million people are estimated to be living with diabetes and that is expected to rise 13.9 million in 2030. While Bangladesh has 3.2 million people with diabetes in 2000 that is expected to rise to 11.1 million by 2030 (Wild et al., 2004). It has been widely recognised that prevalence of age-standardized diabetes is higher in people from South Asian origin compared with white European population (Khunti et al., 2009).

One of the initial indications of higher prevalence of diabetes in South Asian was found in the publication of the Southall Survey in 1985. It was revealed that diabetes is three times higher in South Asians than white populations and five times more in people aged between 40-69 years (Mather & Keen, 1985). According to the Health Survey for England, there is a higher prevalence rate in South Asian: Indian, Pakistani and Bangladeshi men had a higher prevalence of type 2 diabetes aged 35-54 and aged 55+ then

the general population. In women type 2 diabetes is also more common in people from Pakistani, Indian and Bangladeshi origin (Health Survey, 2004). Barnett (1999) also found that 20 percent of people over age 40 from the South Asian community have this condition while another study (Burden, 2001) suggested that 15.2 percent of the South Asian population had diabetes compared with 3.8 percent of the white population. More recent updates from Diabetes UK (2014), have also strengthened the evidence that type 2 diabetes is up to six times more common in people of South Asian descent and is a growing problem in this community. The South Asian community is also at higher risk of type 2 diabetes at the age of 25, opposed to 40 in the White population (Diabetes UK, 2014), which also highlights the need for particular screening and prevention programs for South Asian people (Hanif et al., 2014).

The high rate of diabetes in South Asians is also reported in other countries in Europe, USA and Canada (Lipscombe & Hux, 2007). Higher prevalence of diabetes in South Asians other than in their native countries suggests migration to affluent societies has been a key factor in the rise of type 2 diabetes in this population. There is also the variability of prevalence rate within the different sub-groups of South Asians, with figures particularly high in people of Pakistani and Bangladeshi origin (Health Survey, 2004). This higher prevalence of diabetes in South Asian communities signifies the presence of certain genetic and environmental conditions as risk factors for developing this disease in this community. In the next section genetic, environmental, personal and social/cultural factors were discussed as risk factors for developing diabetes in South Asian people.

3.4.1 Risk factors

Diabetes is a heterogeneous metabolic disease resulting from defects in both insulin secretion and action. The etiology of type 2 diabetes is multifactorial including genetics, as

well as prenatal and postnatal factors that influence several different defects of glucose balance within the body, primarily in beta cell function and also in muscle and liver (Vaxillaire & Froguel, 2010). However, the personal characteristics and lifestyles also contribute as risk factors for developing diabetes (or may trigger an early onset of diabetes). The potential risk factors of diabetes in people from South Asian descent are discussed in the next section.

3.4.1.1   Genes or environment

As discussed earlier, epidemiological studies have shown that the prevalence of diabetes amongst South Asians is significantly greater than in many other ethnic groups (Health Survey, 2004) and is up to six times higher risk of developing this condition than the white European population (Diabetes UK, 2014). Mainly the rise in diabetes attributed towards the environmental factors: obesity, increased life expectancy, sedentary lifestyle, urbanisation and migration to developed countries are all considered risks of developing diabetes in South Asian population (Lipscombe & Hux, 2007). On the other hand, there are factors that suggest the role of genetics in developing diabetes in South Asians. Environmental and genetic factors are both likely to be important in understanding the etiology of diabetes. It is more likely, however, that within populations diabetes risk is determined by a large element of environmental factors, while between population risk factors (ethnic difference in risk) is determined by a large genetic element (Forouhi et al., 2005).

Firstly, the evidence about the role of genetics in developing diabetes is presented. In 1994, UKADS examined the patients from three ethnic groups: white, African Caribbean and South Asian. In an ethnic group of South Asian people, there was highest insulin resistance while people from African-Caribbean origin have lowest. Beta cell

dysfunction was worst in African Caribbean people while least evident in people of South Asian origin. This study raises the question as why there is higher insulin resistance in South Asians than the European and African-Caribbean, with no evidence of beta cell dysfunction. Further emphasis was focused the need for further study on the interaction of genetics and the environment that can play a role in determining these tendencies in this community (UKADS, 2008).

Neel (1962) hypothesised that tendency to insulin resistance was unlikely to be a genetic disorder but rather a thrifty-genotype that have protected individuals during the primitive period of food deprivation. However, within the context of the modern lifestyle, excessive food availability and reduced physical activity and genetic predisposition to insulin resistance had converted this genetic advantage into genetic disadvantage and cause of diabetes in South Asian people.

The thrifty phenotype hypothesis introduces a new area of research to explore the relationship between mother's malnutrition, fetal growth and risk of developing type 2 diabetes. Low birth weight can predict insulin resistance and adiposity in childhood. Yajnik et al. (2008) conducted a study in India to explore the relationship between maternal nutrition and offspring risk of type 2 diabetes and cardiovascular diseases. They demonstrated that the thin-fat phenotype of Indians is associated with a higher risk of type 2 diabetes. This phenotype reflects the simultaneous involvement of two major body compartments (less thin and more adipose), which contribute to the pathogenesis of type 2 diabetes.

There is evidence that type 2 diabetes has a genetic basis: people with a family history of diabetes are at higher risk of diabetes. Some of the genetic influence on diabetes is likely to be mediated through central obesity, and this trait appears to be more closely

under genetic control than obesity in general (Forouhi et al., 2005). Muscle thin but adipose (thin-fat) body composition of South Asian adults contributes to their high risk for type 2 diabetes (Krishnaveni et al., 2005).

People of Indian origin have a characteristic adult body phenotype: a relatively low body mass index (BMI), but increased total, subcutaneous and central (Truncal and abdominal) body fat. They tend to be insulin resistance compared with other populations, and have high rates of the insulin resistance syndrome and type 2 diabetes. Yajnik (2003) conducted a comparison between new-born urban Indian children in India and white Caucasian children from London, to test the hypothesis that the adiposity and hyperinsulinemia of Indians are present at birth. It was suggested by the results that the intrauterine origin of adiposity, central adiposity, and hyperinsulinemia in Indians was present at birth. The tendency of truncal or central obesity is present in Indians even during intrauterine development. In this study, they confirm the characteristics of the thin-fat phenotype of Indians at birth and show that they are also hyperinsulinemic at birth (Yajnik, 2000). The thin-phenotype hypothesis implies that there is the genetic evidence of predisposition for developing diabetes in South Asian people. This genetic predisposition to diabetes highlights the needs to develop the interventions to reduce the risk of developing diabetes in this ethnic population.

Chandalia, Abate, Garg, Stray-Gundersen and Grundy (1999) conducted a study to examine the relationship between obesity and insulin resistance in Asian Indians. South Indian men living in the USA have relatively low insulin sensitivity even with body fat in the normal range, and further, they argued that upper body fat is not the primary cause of diabetes in this population (Chandalia et al., 1999). Comparative studies have reported that for the same BMI as per age and gender Asian have a higher fat percentage compared to Caucasians. Body fat percentage between Asians and Caucasians depends on the ethnicity

and region. South Asians tend to have a higher abdominal fat mass as compared to Caucasian with a tendency to store more fat in the subcutaneous abdominal region (Wulan, Westerterp & Plasqui, 2010).

This genetic tendency also considered a concern for this community as this type of obesity is a clinical marker of developing diabetes, and further efforts can be made to reduce this particular risk factor in this community. Tracing the origin of the thin-fat phenotype in early life may be the key to understanding South Asians susceptibility to later obesity and diabetes. More research is needed into genetics and environmental factors (maternal nutrition and metabolism, postnatal diet and physical activity) that determine early growth and body composition (Krishnaveni et al., 2005).

Ethnic differences in fat have been considered a major contributor to the observed excessive prevalence of insulin resistance and diabetes in the Asian Indians, Japanese and Hispanics, and Native Americans (Abate & Chandalia, 2003). However, Abate and Chandalia (2003) argued that neither obesity nor fat distribution alone can account for the differences in the prevalence of diabetes in ethnic minorities. Insulin resistance in South Asiana might be the interaction between acquired factors, related to western lifestyle and genetic predisposition.

There is a wealth of epidemiological studies that have shown the prevalence of diabetes influenced by the environmental factors (Health survey, 2004; Diabetes UK, 2014; Lipscombe & Hux, 2007). The process of urbanisation is associated with a progressive increase in the prevalence of diabetes in the ethnic groups although there is variation between different ethnic groups. However, ethnicity and susceptibility for diabetes have been observed (Abote & Chandalia, 2003). Moreover, the fact that type 2 diabetes is higher in migrant South Asians (Dowse et al., 1990) highly suggests the role of

the environment in developing diabetes. Cultural and social roles and different lifestyles in ethnic minorities increase the susceptibility of type 2 diabetes (Greenhalgh, 1997).

Environmental inequity as a consequence of living in an adverse physical and social environment is considered higher risk factors for developing obesity and diabetes in people from ethnic minorities and socially-economically disadvantaged groups of these populations (Blackwell, 2009). Individuals living in these areas face many issues including everyday stress, living in an unhealthy environment with poor access to physical activity venues, healthy food supply, and provision of health care services. Further, they may have poor literacy and numeracy skills, poor sense of autonomy and low self-efficacy to change unhealthy behaviour (Ershow, 2009). All the evidence described above clearly reflects the combination of multiple factors that act as a risk for developing diabetes in South Asian people. More personalised personal and culture factors is described in details in subsequent sections.

3.4.1.2 Dietary habits

Research suggests that lifestyle interventions including healthy diet is one of the major benefits in the prevention of diabetes in people who are at risk of developing this condition (Wild & Forouhi, 2009). South Asian community living in the UK is quite a heterogeneous community and the differences are also evident in their dietary patterns (Hanif et al., 2014) that make it difficult to generalise the findings on South Asians considering as one ethnicity. However, there is no certainty that which specific food component of the diet is beneficial or harmful regarding the future risk of diabetes (Wild & Forouhi, 2009). It is also identified that dietary fat as a contributor to insulin resistance in ethnic minorities and this may be enhanced among individual with obesity or who have a low level of physical activity (Abate & Chandalia, 2003).

A South Asian diet is considered to have more carbohydrate, less protein, less fat and more fibre than an indigenous British diet. Cooking practices also vary between South Asian sub-groups, as people from North India prefer to use ghee or clarified butter (Hanif & Karamat, 2009). Wild and Forouhi (2009) also mentioned the lack of research evidence regarding diet and nutrients particularly in diabetic South Asian as much of the research in this area focuses on coronary heart disease and cancer (Wild & Forouhi, 2009). A survey looked into the dietary changes after diabetes in South Asian people explored that the majority of the South Asians continued to consume South Asian food despite the concern that it might be detrimental to their glycemic control (Hanif & Karamat, 2009). Moreover, there are different cultural norms and traditions about food; men have little or no input in cooking (Simmons, Meadows & Williams, 1991). The South Asian traditional foods are considered a source of strength and they also want to eat to minimise the potential alienation from the community (Hanif & Karamat, 2009).

South Asians tend to prefer fried food as compare to steamed or boiled option (e.g. fish), consumption of traditional sweets and fried snacks remained high in this community (Hanif & Karamat, 2009). It was also found that South Asian men and women are not following the dietary guidelines recommended of three meals per day. Meal timings also vary between South Asian and European, as in South Asian breakfast considered to be light while the heavy meal is eaten quite late at night, which may influence the advice on medication use and timings (Simmons et al., 1991). Consumption of fruits and vegetables is lower in South Asians particular people from Bangladesh who have the lowest intake of fruits (Joshi et al., 2007), and eat more red and fatty meat whereas Pakistani man and women have the lowest vegetable consumption (Health Survey, 2004). However, Uskel and Platt (2014) have identified that people who stick more with the traditional ethnic diet tend to have more consumption of healthy food (e.g. vegetables and fruits).

South Asian people have a common practice of prolonged cooking of vegetables that might destroy the essential vitamins which to some extent undermine the fact that meals are often cooked from scratch with fresh ingredients (Joshi et al., 2007). Dietary habits and cooking traditions can have an influence on increasing the risk of developing diabetes, and it can worsen the diabetes control if the area of a healthy diet is missing in their diabetes self-management regime.

3.4.1.3 Physical activity

Moderate physical activity can improve glycemic control, improve cardiovascular health, functional status and promoted longevity (Hay & Clark, 1999). Regular exercise and dietary modifications can prevent 58% of type 2 diabetes in people at high risk of developing this condition (Lawton, Ahmad, Hanna, Douglas & Hallowell, 2006). The lower level of physical activity is a well-established risk factor for diabetes. Current evidence on physical activity levels suggests that these levels are lower in South Asian adults compared with other ethnic groups (Fischbacher, Hunt & Alexander, 2004). There is considerable variance in different sub-groups of South Asians about physical activity, for example, leisure time physical activity is culturally unacceptable for most Muslim women (Joshi et al., 2007), particularly Bangladeshi women, who have the lowest level of physical activity (Fischbacher et al., 2004).

The Health Survey of England (2004) documented the lower level of physical activity in South Asian as compared to other ethnic groups. Low levels of physical activity were recorded in Pakistani and Bangladeshi men (51%), while this level is even lower in women (Bangladeshi 68% and Pakistani 52%). There were just 11% of the Bangladeshi men and 15% of the Pakistani men who met the criterion for at least 30 minutes of moderate physical activity for five days a week (Health Survey, 2004).

Although there is a reported low level of physical activity in South Asians, this difference becomes more apparent with advancing age (Fischbacher et al., 2004), and this difference is even greater among Indian women and Bangladeshi men and women than among the corresponding general population (Health Survey, 2004). Bangladeshi was the least and Indians were the most physically active South Asian populations (Bhopal et al., 1999). There is limited data available to look into the physical activity level in native South Asian groups but available evidence suggests a lower level of regular exercise in native South Asians as compare to other regions (Joshi et. al, 2007) that suggest the limited habit of taking structured physical activity in South Asian culture. Lawton et al. (2006) identifies the barriers to doing exercise among South Asian people, that is a complex interaction of social, religious, cultural and economic reasons. Lack of time, family commitments, weather conditions and lack of socialising in outdoor sport and other activities were some of the barriers.

There were mixed thoughts among South Asians about the concept and process of exercise. South Asian women particularly emphasised being active day to day rather than the western concept of organised physical activity (Hanif & Karamat, 2009). Particularly people with diabetes more feel that exercise is a threat to their health as diabetes had already made their body weak (Lawton et al., 2006). Exercise options also vary in South Asians; swimming and walking are considered favoured exercise while running is least popular among South Asian females (Hanif & Karamat, 2009). A report of Health Technology Assessment (2002) suggested that more South Asian women were willing to do exercise if it is prescribed by their healthcare professional and this can be particularly effective to work with people who are a risk of obesity or obesity-related medical conditions (Carroll, Ali & Azam, 2002).

Although there are less objective measures used to assess the level of physical activity in South Asian people, still the available findings suggest it a concern for this ethnic community (Hayes et al., 2002). Importantly there is less physical activity recorded in South Asian children who are 13 times more likely to develop type 2 diabetes than white European children (Diabetes UK, 2014). The lower level of physical activity is a concern, and it needs to be addressed to reduce the risk of diabetes and improve management while living with this condition in this community.

3.4.1.4   Smoking

Smoking is considered an independent risk factor for type 2 diabetes (Cho, Chan, Jang, Lim, & Choi, 2009). The prevalence of smoking and alcohol consumption is markedly lower in women compared to men in South Asian communities (Joshi et al., 2007). The higher rate of smoking in Bangladeshi men (82%) has been reported from East London (Chowdhury, Lasker & Mahfuz, 2006) whilst lower in Indians and Pakistani men (Bhopal et al., 1999). Consumption of *betel nut* (the astringent kernel of the seed of the betel palm, chewed in many tropical regions in combination with slaked lime and the leaves of the betel nut plant) is also common in North Indians and Bangladeshis with an overall 66% prevalence rate in British Bangladeshis (Hanif & Karamat, 2009., Donaldson, 1986).

3.4.1.5   Obesity

Obesity is a major risk factor for diabetes (Handy, Boarnet, Ewing & Killingsworth, 2002) and a higher rate of obesity has been observed in ethnic minorities living in Western countries particularly with the high waist-hip ratio (Greenhalgh, 1997). In the UK, obesity is indicated by BMI. People from the South Asian community have a risk of developing diabetes at lower BMI as compared to White population (Diabetes UK, 2012). People of

Indian origin have a relatively low BMI but increased total, subcutaneous and central (Truncal and abdominal) body fat (Yajnik & Yadkin, 2004).

In 2004, the WHO reviewed the BMI for determining the cut-off point for overweight and obesity in the Asian population. In South Asians BMI greater than 27.5kg/m2 considered obese and greater than 23 kg/m2 as overweight. Misra et al., (2009) presented data from India and suggest that the appropriate cut-off for defining obesity in people from Indian sub-continent would be a BMI > 23 for overweight and BMI >25 for obesity. In the UK, the prevalence of obesity in South Asian men was around 14% and in women was 20% while with age over 35 years, and with BMI >25, prevalence was 53% for men and 55% for women (Health Survey, 2004). However, if the lower cut-off score (BMI) as presented by Misra et al. (2009) applied than these estimates can go much higher and necessitate the need to develop intervention targeted to this particular ethnic group in reducing the obesity that is an independent risk factor for developing diabetes.

3.4.1.6 Cultural and religious factors

Culture can be defined in several ways: it can be considered as a set of distinctive material, spiritual, intellectual and emotional features that can be manifested in art, literature, lifestyle, value systems, traditions and beliefs of a society or a social group (Spencer-Oatey, 2008). There is considerable evidence available that suggests South Asians in the UK have unique cultural traditions and lifestyle habits. The differences can act as a barrier to adopting healthy behaviours that negatively impact on the provision of diabetes care in South Asian people in the UK (Hanif et al., 2014). Healthy and balanced diet and exercise are an important part of the diabetes management, and cultural practices have a huge effect on the life of an individual with diabetes.

People from ethnic groups have different health needs compared to the native population in the western countries. The concept of what is healthy and what is not is also varied within different cultures. People from the South Asian community have a strong tradition of classification of food as cold and hot and a disease considered hot can be treated with cold food and vice versa (Bhopal, 1986). South Asian people may have a different attitude to health, they often have a fatalistic attitude towards health and seek help much later that can have an effect on diagnosis of the disease. Lawton, Ahmad, Hanna, Douglas, Bains and Hallowell (2008) analysed the causal factors of type 2 diabetes in white and people of South Asian community. There were different perspectives regarding the cause of diabetes in both populations. South Asians attributed their diabetes to the external factors, like migration to the UK, being poor and less educated as compared to the native people and to prevent diabetes is inevitable, while white people take the responsibility of being diabetic and attribute it towards their lifestyle as a cause of diabetes. It is true that migration has opened up new challenges to South Asians, as they have to encounter a new socio-cultural environment that often influences their health (Greenhalgh, 1997). The conflict between adherence to old cultural traditions and integration within the new environment can be challenging and stressful (Hanif & Karamat, 2009). Differences in cultural traditions and lifestyle were well-documented in South Asians and white population (Barnett, Dixon, Bellary, Hanif, O'Hare & Raymond, 2006).

There are some religious rituals that are also important to consider in South Asian people. A large number of people from the South Asian community fast either on a regular basis (Hindus fast one each day in a week) or as part of religious observance (Muslims during Ramadan) (Hanif et al., 2014). It is a particular challenge to advise South Asians to fast safely as part of diabetes management because the risk is there that fasting may lead to hypoglycaemia, hyperglycaemia and dehydration (Bellary, 2010; Hanif et al., 2014). Some

people may feel reluctant to take their medication during fasting, and on the other hand, some people broke their fast with a feast which could have a significant impact on glycemic control. The consideration of religious rituals highlights the need for detailed advice on the dosage and timings of medication for people with diabetes before fasting (Hill, 2006).

The Muslim Council of Britain, Diabetes UK and the American Diabetes Association have produced detailed recommendations for managing diabetes during Ramadan (MCB, 2014; Ali et al., 2016; & Al-Arouj, 2010). In addition to fasting, South Asians (Muslims) are also obliged to make a pilgrimage (Hajj) to the sacred mosque in Makkah at least once in their lifetime. Hajj involves travelling to a country with different climate and is considered physically demanding as walking for distances in the heat and strong sun and standing in the desert of Arafat (Place in Makkah), so this would also require adjustments to medications along with appropriate education (Hill, 2006).

Many healthcare professionals believe that people from South Asian origin have different perspectives towards chronic medical conditions which are life-long and require continuous treatment and supervision. There is also a tradition of using alternative or complementary treatment (i.e. herbal, spiritual) for diabetes that may lead to poor compliance with the medication (Bellary, 2010). In some cases, they seek alternative treatment for their condition with their cultural frame of mind that there will be some magic cure available that can have the cure for their condition and that seems beyond the notion of modern science. Particularly in diabetes, the discontinuation of on-going medical treatment results in the poor diabetes control and other health-related problems (Nagi, 2004). The discussed cultural traditions and norms reflect the consideration of specific needs for this distinctive ethnic community within healthcare sectors and highlighted the provision of health related information according to their needs. Apart from these shared

cultural perspectives some of the personal factors can also be important to consider such as language and education. Particularly English as a second language impact upon the access, navigation and utility of the needed health care services for some of the South Asian people living in the UK.

3.4.1.7   Language and education influence

It was estimated in 1977 that over 200,000 adults in the UK could not speak English fluently, the majority being Asian (Hawthorne, 1994). With the passage of time, this figure has decreased, but it still affects a large proportion of older people, first generation immigrants. South Asians belonging to first generation migrants are now in their 50s and 60s, have little or no education, and are unlikely to be literate at this age, so there is a need to look for other innovative ways to educate them (Hawthorne, 2001). Hawthorne also emphasised the need to learn techniques of concentration, learning and prioritisation first before getting benefit from the health education material. South Asian women with no education had moderate improvement in knowledge after educational interventions, but there was less improvement observed in glycemic control. That suggests that illiteracy and lack of educational experiences can be a greater challenge in effective health education (Hawthorne, 2001).

The 2011 Census asked for the English language proficiency of the ethnic minorities in the UK which included a self-reported question about their subjective assessment of English language proficiency. Overall 86% of the Indian-born residents reported themselves as English proficient, in contrast, the Bangladeshi-born population had the highest proportion of non-proficient English speakers (30%), while (42%) of Pakistani reported themselves as proficient in English language (Office of National Statistics, 2011b).

A large majority of the South Asians migrated to the UK have poor English language proficiency that can lead to the communication problems with the healthcare professionals (Stone, Pound, Pancholi, Farooqi & Khunti, 2005). Bissell, May and Noyce (2004) suggest that communication with the patients should not simply take as an opportunity to provide instructions around treatment. A relationship should be considered as space where the expertise of patients and healthcare professionals can be pooled towards effective healthcare delivery. Communication difficulties is an umbrella term for a variety of linguistic and cultural problems that affect the process of understanding between health care professional and patients (Hawthorne, 1994).

Fagerli, Lien and Wandel (2005) conducted a study with South Asians in Norway and suggested that healthcare providers would benefit from (and can expand their knowledge of) the many positive aspects of ethnic minorities' food, culture and its relevance to diabetes and can apply their knowledge thereafter, whether it concerns food, cultural tradition or impact of religion in everyday life (Fagerli, Lien & Wandel, 2005). Healthcare professionals might not be able to understand the symptoms expressed by all patients which can end in inaccurate diagnosis. Sometimes advice given in the English language is not well understood by the patients. As a result, there is a misunderstanding of the instructions, poor adherence to the treatment and missed appointments (Bellary, 2010).

South Asian women who cannot read are more likely to have poor glycemic control and find it more difficult to learn how to apply the acquired knowledge in day to day life activities (Hawthorne & Tomlinson, 1999). This can effect their treatment options according to their condition of diabetes; communication difficulties can act as one of the factors in reluctance to go for insulin therapy despite poor glycemic control. The poorer glycemic control in South Asian females along with poorer knowledge of diabetes in the areas of self-monitoring management and diabetes complications may be due to their lack

of education in the past and their inability to speak and read English. This suggests that women with lower educational status are likely to have more intensive, culturally appropriate, health education. The level of education was linked with knowledge about the chiropody service and diabetic complication confirming the patient's background knowledge in using the UK healthcare services for diabetes is important to consider (Hawthorne & Tomlinson, 1999).

However, people from the South Asian community feel anxious and ready to have more knowledge and information to change their behaviours and have better control of their health. Although some of the South Asian population do not necessarily eat healthily or apply their knowledge to difficult situations despite having an adequate level of knowledge and information (Hawthorne & Tomlinson, 1999). This highlights the need to provide more information on 'why' they need to change their unhealthy behaviour as part of health promotion. These personal factors along with cultural and social norms and traditions can have a significant effect on the access and utility of the services both in a case of living with diabetes or using preventive services to prevent/delay the development of diabetes. The area of access and utility in relation to diabetes in South Asian people discussed in detail in the subsequent section.

3.4.1.8   Access to health services

The English National Health Service (NHS) aims to provide comprehensive medical and nursing care to all its citizens free of cost. It was expected that it would reduce the morbidity and mortality rate as more people will have free access to services (Hawthorne, 1994). The Department of Health (2000) also emphasises universal access to healthcare services for all based on clinical needs not on the ability to pay (DoH, 2000a). Smaje and Le Grand (1997) acknowledged that access to healthcare services is an important factor in

determining health status. Since the publication of the Black Report in 1980, it has been documented there are still inequalities in different groups of the population. Although many alterations have taken place within the NHS, it is still a challenge to meet the needs of local communities in a multicultural and multiracial society that has become today's Britain. People from the South Asian community may not be the under user of healthcare services, but they can face different problems in gaining access to quality medical care due to communication and cultural barriers.

People from some communities may prefer not to go for mixed clinics (male and females together) and find it unacceptable to attend any health education sessions by sitting next to a stranger (Hawthorne, 1994). Female patients may prefer to choose a male Asian general practitioner (GP) as compared to female non-Asian GP to overcome the communication difficulties in the English language. But this raises another issue for females as they are reluctant to discuss their gynaecological issues with the Asian male doctor (Ahmad, Baker & Kernohan, 1989). People from the Bangladeshi community face more difficulties in accessing their GP than the general population (Rudat, 1994).

People of the South Asian community are also at a disadvantage as a user of healthcare services. Madhok, Bhopal and Ramaiah (1992) examined the experiences of Asian and non-Asian patients in the hospital setting. They found a difference in communication and language between two groups. Asian females prefer to have a check-up by female doctors. Meals provided in the hospital rarely meet the needs of people of ethnic minorities and there was an increased satisfaction about hospital food after providing required Asian food. Muslim patients find it difficult to offer prayer and have difficulties in making ablutions before prayer. They may also struggle to understand the information leaflets that are mainly presented in the English language and if there is some

information translated in a native language that might also contain grammar and spelling mistakes (Hathorne, 1994).

Shaukat, de Bono and Cruickshank (1993) conducted a study in Leicester that suggest that the South Asian patients have to wait longer for a referral to cardiology clinics as compared to their white counterparts. Authors have suggested few factors that might count towards this late referral: seeking treatment late, language difficulties, different perception of symptoms and in some cases maybe there is GP bias in giving less weight to the symptoms reported by South Asians patients (Shaukat, de Bono and Cruickshank (1993).

Anderson, Scrimshaw, Fullilove, Fielding and Normand (2003) pointed towards the role of organisations and professionals in creating barriers to the provision of equal access to all sections of society. Location, long waiting times, short consultations, inconvenient appointment times, repeatedly cancelled appointments, and poor facilities can act as organisational barriers to accessing services (Penchansky & William, 1981). Unequal provision of information about the services available can prevent the patients from seeking access to the services and choices about treatment options may not available (Barnes & Prior, 1995). South Asian people with diabetes were largely unaware of the range of services they can use to manage their diabetes. There were few people from this ethnic minority who were offered any choice that enables to improve their situation. They exhibited a fatalistic acceptance of poor standards of care and a sense of helplessness about accessing better quality services in the management of diabetes (Rhodes & Nocon, 2003).

There are inequalities in ethnic minorities in healthcare and to blame communication difficulties and cultural practices are an oversimplification of the issue; rather it is part of the wider inequalities ranging from poverty, housing and education

(Hathorne, 1994). Donaldson (1986) suggested that few elderly South Asians received the community services and services such as meals on wheels, home help, social workers and particularly chiropody services were not known to them (Donaldson, 1986). There was a significant difference observed about blood pressure, and creatinine checked in South Asians and White diabetic patients. This suggests differential attendance rates in secondary and primary care by ethnic groups and white patients with diabetes (David & Kendrick, 2004).

Lear, Lawrence, Burden and Pohl (1994) suggested that despite the higher risk of developing myocardial infarction in South Asians than their European counterparts, less rates of referral can be observed for coronary angiography. Few South Asians were referred for exercise stress testing, and so far reasons for non-referral are unclear. However, they suggest that poor communication and real or perceived poor exercise tolerance may play a role. The use of an interpreter and information leaflets in a different language can solve this issue.

English people are more likely to attend hospital diabetes and GP clinics than South Asians (Goyder & Botha, 2000), despite the higher rates of diabetes and diabetes mortality in South Asians than the general population (Shah & Kanaya, 2014). People from the South Asian community are more likely to receive renal replacement therapy because of end stage renal failure believed to be associated with diabetes (Roderick, Clements, Stone, Martin, & Diamond, 1999). This could be due to the poorly controlled diabetes and high blood pressure but whether this could be due to health-seeking behaviour at the individual level, or an organisational issue of poor access to specialist care, remains unclear (Arai & Harding, 2002).

The limited use of professional interpreters, and dependence on family members who are not proficient in the English language either, put minority patients and carers in a disadvantage position. In some cases, healthcare professionals were also dissatisfied with the relatives as interpreters with limited English proficiency or limited knowledge of medical concepts because that can lead to inaccurate interpretation of the symptoms (Garish, 2001).

Alam, Speed and Beever (2012) conducted a scoping review of the literature to identify the experiences and preferences of the Bangladeshi patients and carers in accessing diabetes-related health care. Language and literacy were the most common barriers hindering access to information and services. It was also found that patient's knowledge about diabetes and its management was low. Relatives acting as interpreters and a source for information were also high in this context. They highlight the need to integrate social networks with religious and cultural beliefs as well as wider societal duties as playing a crucial role in accessing information and services for this population.

Where communities are not offered reasonable opportunities for equal access to (and benefit from) health care services, there are clinical consequences such as poorer health, higher mortality, reduced longevity, greater disease burden and consequently inequity (Marmot, 2010). Despite the remarkable efforts made by the local and national government to reduce inequalities in the access and utility of health services (DoH, 2001; DoH, 2010) there remains a disparity in certain populations of society i.e. ethnic minorities (Atkinson et al., 2001; Randhawa, 2007).

The providers' lack of cultural understanding (and effective use) of communication may be a barrier to improving access. In medical consultations, the perception of physicians as expert and authority figures expecting compliance, makes some South Asian

patients feel misunderstood. Discrepancies between patient and healthcare provider views about their roles also extend beyond ethnic differences to include both class and education. The use of an interpreter is recommended to improve communication along with the need to adopt culturally sensitive services (Wilson, Alam, Latif, Knighting, Williamson & Beaver, 2012). Culture is not a rigid factor in changing lifestyle habits and patterns. Bhopal (1986) have shown that if the people are approached in a culturally sensitive manner and received effective communication that can be helpful in advocating changes in lifestyle and the use of preventive services. This thesis has the primary aim to study (understand) health literacy needs of the South Asian people living with diabetes in the UK. The passion is to understand health literacy within cultural perspective of South Asian people that will illustrate the potential assets/risks of this particular ethnic community and enable us to identify the areas for future interventions to improve the management of diabetes.

3.4.2   Summary

Steadily increase in the global epidemic of diabetes highlights the need to consider effective intervention to prevent and effectively manage this condition. Type 2 diabetes is a particular concern. The WHO (2016) suggests an estimated 422 million adults were living with diabetes in 2014 around the globe. The increasing number of people with diabetes and its complications is likely to place a huge burden on health care resources. People from South Asia are at a higher risk of developing this condition. Risk factors for diabetes are multidimensional including genetic susceptibility and individual/environmental factors. Research has demonstrated that people from the South Asian community have a genetic predisposition for diabetes. Cultural diet patterns, less or no physical activity, and other cultural and religious factors play an important role in developing this condition. South Asians living in the UK can have further risks involving access and utility of healthcare

information due to limited English language proficiency that can increase the risks of developing diabetes and its associated complications.

3.5 Prevention of diabetes

Diabetes is a preventable disease and risks can be reduced by lifestyle interventions and medications. Intervention for people at risk of developing diabetes considered effective in preventing diabetes. Simple and reliable tests can be utilised to screen people who are at risk of developing this condition (NICE, 2012). The Da-Qing Diabetes Prevention Study (2008) from China raised some general points in their randomised controlled intervention study:

- Lifestyle intervention (diet and physical activity) significantly reduce the risk of developing diabetes for six years. Both diet and exercise have a similar effect in reducing the risk of diabetes.
- Reduction of weight was also effective in reducing the risk of diabetes.

These findings are considered applicable to educate the people who are at risk of developing this condition, but there is need to evaluate and assess the applicability of these findings to others groups at higher risk of developing diabetes (Pan et al., 1997). Obesity is considered an independent risk factor for developing diabetes. The UK Government in the budget of 2016 announced "The Soft Drinks Levy (SDIL) identifying sugar tax as playing a key part to reduce childhood obesity. This tax directly targets the products and importers of sugary soft drinks to encourage them to remove added sugar, promote diet drinks, and reduce portion sizes for high sugar drinks (HM Treasury & HM Revenue and Customs, 2016). As discussed earlier, diabetes and associated complication have a huge burden on NHS budget and earlier prevention through changed lifestyle can reduce the risk of developing diabetes. Diabetes can be described as deadly, but at the same time, it is a

preventable disease. Diabetes triggered by bad diet and lack of exercise and lifestyle changes can be helpful to reduce the risk of developing this condition. However, a diabetic person with better self-management (i.e. healthy and balanced diet, physical activity, medications) can reduce the risk of developing complications associated with diabetes.

3.6   Management of diabetes

The management of diabetes includes management of symptoms, psychosocial consequences, lifestyle changes (i.e. diet, exercise), monitoring blood glucose levels, adjustment of medication and awareness of the recognition of possible complications (Barlow, Sturt & Hearnshaw, 2002). The goal of diabetes management is lower blood glucose levels to prevent long-term medical complications (Barlow et al., 2002). Lifestyle programmes should be considered as part of the multidisciplinary intervention programme for all diabetic patients. Appropriate management of cardiovascular risk factors such as smoking, physical activity and balanced diet is important for the prevention of macrovascular disease. However helping people to modify their behaviours also needs the motivation at the individual level to change their perception towards diabetes and to understand the potential for complications associated with diabetes in later life (Ghosh & Collier, 2012).

The NHS in the UK has a leading role in the delivery of high-quality healthcare for individuals with diabetes. Also, the government has launched National Service Framework (NSF) for common diseases including diabetes. The NSF for diabetes set standard for the care of patients with diabetes (DoH, 2001). One of the main aims of the NSF is to reduce inequalities in diabetes care and also improve the overall quality of life of people living with this condition (Nagi, 2004). South Asian people in the UK have been treated for their diabetes using the same model of care developed for the indigenous white population with

diabetes. There is still a need to explore the barriers to the provision of culturally specific diabetes care for the people of this ethnic minority in the UK. These barriers might be personal, including health beliefs, cultural and language barriers, community barriers, issues of trust and understanding between this population and the healthcare providers, and psychosocial barriers (Nagi, 2004). There is a great need for health care professionals to familiarise themselves with the impact of ethnicity in relation to diabetes. This will help to refine treatment strategies and educational issues for each ethnic group, which will lead to improved health outcomes and better quality of life (Abate & Chandalia, 2003). Management of diabetes requires personal responsibility as much of the care lied in the daily life of a diabetic. Self-management is considered central as per nature of the chronic condition; next section discusses the self-management aspect of diabetes.

3.6.1   Self-management of diabetes

Self-management in chronic illnesses refers to the daily activities that individuals undertake to keep control of the illness whlist minimising its impact on physical health, daily functioning and to cope with the psychosocial phases of the illness (Clark, Becker, Janz, Lorig, Rakowski & Anderson, 1991). Self-management includes capabilities such as insight into disease mechanisms, self-monitoring, knowledge, skills, and making use of behavioural change techniques such as goal setting (Koetsenruijter et al., 2016). Many of the most common chronic diseases such as heart disease, arthritis and diabetes entail a significant self-management component (Kennedy, Rogers & Bower, 2007) such as medicine taking, physical activity, dietary and weight management and specific disease-related behaviours (Gallant, 2003). Self-management of chronic illness has been widely recognised as an essential part of chronic illness care, as it empowers patients and improves health outcomes (Van Houtum, Rijkin, Hijmens & Groenewegen, 2015).

Self-management in chronic disease can be defined as:

> "The individual's ability to manage the symptoms, treatment,
> physical and psychosocial consequences and lifestyle change
> inherent in living with a chronic condition. Efficacious self-
> management encompasses the ability to monitor one's condition and
> to affect the cognitive, behavioural and emotional responses
> necessary to maintain a satisfactory quality of life. Thus a dynamic
> continues the process of self-regulation is established with the patient
> and health care provider working in successful partnership" (Barlow,
> 2001, p. 547).

The concept of "self-care" and "self-management" are sometimes used interchangeably, however, distinctions do exist between them. Self-care is viewed as a preventive strategy in which tasks performed by healthy individuals at home; whilst self-management is concerned with the daily tasks undertaken by the individuals to control or reduce the impact of disease on physical health status (Barlow, 2001).

There is plenty of research available that explores self-management about diabetes (Cavanaugh et al., 2008; Brega et al., 2012; Vassay, O'Brien, Waxler, Park, Delahanty & Florez et al., 2012; White et al., 2010., Mbaezue, Mayberry, Gazmararian, Quarishi, Ivonye & Heisler, 2010.; Brega et al., 2012). Gallant (2003) has highlighted some of the factors that include: firstly, the growing number of people with diabetes around the globe and its diagnosis around the lifespan; secondly, a person with diabetes has to perform several self-managing tasks; dietary management, exercise, medication management, blood glucose monitoring, and foot care. Thus the nature of diabetes itself leads towards self-

management perspective, and it has been considered an important and accepted part of the clinical treatment of diabetes (Gallant, 2003).

The real challenge in self-management of diabetes is to keep blood glucose under control. Self-monitoring of blood glucose (SMBG) is a commonly used strategy for both type1 and type 2 diabetes and is considered a fundamental component of self-management of diabetes. Self-monitoring guides adjustment of insulin or other medications for patients and healthcare professionals as part of a comprehensive package of diabetes care; encourages self-empowerment and promotes better self-management behaviours. Frequent blood glucose monitoring is associated with an improvement in glycaemia (Ghosh & Collier, 2012).

However, adherence to treatment and self-management alone are not sufficient (Glasgow & Eakin, 1996) and can lead to poor glycemic control. Poor self-management has been attributed to a lack of knowledge, attitude, motivation and personal skills (Penning-van der Eerden, 1990). It is important to have effective education for diabetics as there is a fourfold increased risk of complications among patients who had not received outpatient education as compared to those who had (Barlow et al., 2002).

As mentioned earlier, there is established evidence available that diabetes and its related complications are responsible for a huge individual and public health burden of suffering at present and it is projected to continue in the future (Kntish, 2016). There is great need to deliver diabetes care that improves glycemic control, and effective educational interventions are an important part of diabetes care (Norris, Lau, Smith, Schmid & Engelgau, 2002). Health literacy as an asset also based on to improve health outcomes through health education and health promotion. The health literacy perspective in relation to diabetes is discussed below.

3.7 Health literacy and diabetes

Health literacy has been theorised to be one of the important, non-clinical factors that can reduce the risk of developing complication in diabetes. Health literacy in the context of diabetes management includes a constellation of skills that are critical to patients in managing their condition and navigating health care services. These skills included: cultural and conceptual knowledge, aural and oral literacy (listening and speaking), print literacy (writing and reading), and numeracy (ability to use and understand numbers) (Baily et al., 2014). Health literacy skills specific to diabetes management includes: reading labels on the pill bottles, following writing and verbal directions, comprehending the instructions, appointment information, educational brochures, and informed consent documents (Schillinger et al., 2002). Numeracy is fundamental to diabetes self-management in understanding medication dosage, test results, insulin requirement and interpreting food labels (Osborn et al., 2010). Health literacy is discussed within different perspectives of diabetes; measurement of health literacy; its association with health outcomes; self-management and effective utility of the healthcare information and services as part of diabetes management in the following section.

3.7.1 Health literacy measures and diabetes

Studies examining health literacy in patients with diabetes generally used measures of general literacy and numeracy (e.g. Wide Range Achievement Test, National Adult Reading Test), general health literacy/numeracy (e.g. Short-Test of Functional Health Literacy in Adults (S-TOFHLA), Rapid Estimate of Adult Learning in Medicine (REALM), Newest Vital Sign, Brief Health Literacy Screen, Subjective Numeracy Scale). Although there are health literacy scales developed particular for the patients of diabetes

e.g. Diabetes-Specific Diabetes Numeracy Test-15 (DNT-15) (White, Osborn, Gebretsadik, Kripalani & Rothman, 2011), DNT-Adolescent and DNT-14 Adolescent (Mulvaney, Lilley, Cavanaugh, Pittel & Rothman, 2013), Diabetes-Specific Health Literacy Index (DHL) (Yamashita & Kart, 2011), Literacy Assessment for Diabetes (LAD), (Nath, Sylvester, Yasek & Gunel, 2001), Spoken Knowledge in Low Literacy in Diabetes Scale (SKILLD) (Jeppesen, Hull, Raines & Miser, 2012).

Some researchers considered diabetes-specific health literacy scales more valid than general health literacy measures (Cavanaugh et al., 2008). There is a significant advancement in the development of the diabetes-specific scales although there has some limitation recorded with these scales. Mainly the scales developed for health literacy focus on the measurement of literacy and computational skills and assess the narrow definition of health literacy construct. The missing areas related to health literacy and numeracy also has observed in the scales developed particularly for diabetes. Oral literacy, cultural and conceptual knowledge, understanding the ability to apply the information, and numeracy skills also need to include having an understanding of the broader social and personal factors that can have an impact on the management of diabetes and health literacy. Numeracy is particularly important for a patient with diabetes as they have to do some self-management tasks that involve adequate numeracy skills (e.g. medication management, interpretation of glucose meter readings, adjustment of insulin, dietary assessment) (Rothman, Montori, Cherrington & Pignone, 2008). More robust measures to assess how different aspects of health literacy and numeracy can affect patient's self-management and decision making would better elucidate how to address health literacy/numeracy barriers in self-management for future interventions for improving diabetes management (Baily et al., 2014) with improved health outcomes.

3.7.2 Health literacy and diabetes outcomes

As discussed in Chapter 2 (p.46) health literacy is important to manage health and especially self-management of chronic conditions. In this section, the focus will be on health literacy in the context of diabetes management. Sudore, Mehta, Eleanor, Simonsick, Harris and Newman et al. (2006) conducted a study with more than 2500 community-dwelling older people and concluded that health literacy independently associated with higher prevalence of diabetes in this population. A number of studies have recorded the association between health literacy and diabetes-related knowledge (Bains & Egede, 2010; Brega et al., 2012; Mancuso, 2010; McCleary-Jones, 2011; Powell et al., 2007; Gazmararian et al., 2003; Dewalt al., 2007; William et al.,1998; Kim et al., 2004).

Brega et al. (2012) highlighted the significant association between diabetes knowledge and health literacy, but there was no significant association observed between health literacy and physical activity level in people with diabetes. Powell et al. (2007) stressed have to have educational interventions according to the health literacy level along with consideration of the social determinants that can improve self-management of diabetes.

3.7.2.1 Self-management

There were mixed results being demonstrated by the association between health literacy and self-management (Cavanaugh et al., 2008; Brega et al., 2012; Vassay, O'Brien, Waxler, Park, Delahanty & Florez et al., 2012; White et al., 2010., Mbaezue, Mayberry, Gazmararian, Quarishi, Ivonye & Heisler, 2010.; Brega et al., 2012). Some recent studies illustrate significant relations between health literacy and self-management (Cavanaugh et al., 2008; Brega et al., 2012; Vassay, O'Brien, Waxler, Park, Delahanty & Florez et al.,

2012; White et al., 2010). However, few did not find any association between health literacy and self-management of diabetes (Mbaezue, Mayberry, Gazmararian, Quarishi, Ivonye & Heisler, 2010.; Brega et al., 2012). These results thus suggest the variability of the population samples and also a broad range of self-care behaviours as part of the studies (i.e. diet, exercise, foot care, blood glucose testing) limit the generalisation of these findings.

An adequate level of health literacy has been associated with glycemic control (Schillinger et al., 2002). Low health literacy is a potential barrier to self-management for people with diabetes (Kim & Lee, 2016). Diabetic patients with low health literacy level may find it difficult to navigate and act upon the large number of recommendations on diet and physical activity behaviour (Friis et al., 2016). However, Kim et al. (2004) found no association in health literacy and healthy behaviours in people with diabetes that might be due to the limited sample size. Friis et al. (2016) thus suggest that individuals with diabetes with low health literacy levels find it hard to adhere to the recommended treatment guidelines and find difficulty to understand health-related information. Karter and colleagues (2010) found a link between health literacy and a patient's willingness to initiate newly prescribed insulin treatment. Bauer, Schillinger, Parker, Katon, Adler and Adam (2013), examine the health literacy association with antidepressant medication adherence in diabetic patients. They suggest that patients with limited health literacy were less likely to have prescribed medications and showed less involvement in antidepressant therapy. Another study conducted by Bains and Edge (2011) found no difference in medication adherence in patients with adequate health literacy in comparison to the patients with inadequate health literacy.

There are also mixed results about the association between health literacy and glycemic control in diabetes patients. Brega et al. (2012) found a positive association

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between health literacy and glycemic control in a study conducted with Native Americans and Alaska Native. However, other studies did not find any association in their studies between health literacy and glycemic control (Cavanaugh et al., 2008; Mancuso, 2010). The numeracy components of health literacy are reportedly important in glycemic control (Cavanaugh et al., 2008; Marden, Thomas, Sheppard, Knott, Lueddeke & Kerr, 2012) and it was also significant in explaining racial disparity in glycemic control among people living with diabetes (Osborn et al., 2009). Apart from improving health literacy at an individual level, it is also important to consider in the health care settings (i.e. access and utility, communication with health care providers, shared decision making).

3.7.2.2   Effective patent-provider communication

Effective patient-provider communication has been linked to patient comprehension, recall, satisfaction and improved health outcomes (Stewart, 1995., Piette, Schillinger, Potter & Heisler, 2003; Hadlow & Pitts, 1991). Reciprocal communication between provider and receiver is particularly important for the people with diabetes, a condition with significant self-management demands, and for patients with barriers to communication such as limited health literacy (Castro, Wilson, Wang & Schillinger, 2007). Limited health literacy is also problematic for people with diabetes in their interaction with the healthcare providers. For example, Schillinger, Bindman, Wang, Stewart and Piette (2004) conducted a study with 408 diabetic patients. Health literacy was assessed through the use of S-TOFHLA and results suggest patients with limited health literacy were more likely to report worse communication with the healthcare providers. Poor health literacy was associated with communication problems in the domain of clarity, explanation of condition, and explanation of the process of care. This study also suggests

that limited health literacy may also be a marker for oral communication problems, particularly in the technical, explanatory domains of patient-provider interaction.

Diabetes patients with limited health literacy have also been associated with low rates of comprehension of medical terminology used by the health care providers. Limited health literacy can also be conceptualised as a functional mismatch of the skills of the individual sand the demands placed on the individual by the health care system and its providers (Castro et al., 2007). In another study patients with diabetes suggested that people with limited health literacy were more likely to report that their diabetes could be better controlled if they had effective communication with the healthcare providers and their desire to have self-management support to improve their condition (Sarkar, Piette, Gonzales, Lessler, Chew & Reilly et al., 2008).

Patients with limited health literacy skills are also less likely to use the technologically based mode of communication. For example, use of online patient portal for communication with health care providers even when they had computer access and had registered with the portal (Sarkar, Kartar, Liu, Adler, Nguyen & Lopez et al., 2010). This ineffective communication can also impact upon the shared decision making in the healthcare process. Patients with limited health literacy do not want to take part in shared decision-making processes as part of a care plan (DeWalt et al., 2007). It has demonstrated that level of health literacy is important in the range of health care processes; from access and utility for healthcare services and self-management process. Failing to have effective self-management can lead towards the development of complications associated with diabetes.

3.7.2.3   Diabetes complications

Low health literacy has been associated with more diabetes-related complications (Schillinger et al., 2002) and improving health literacy seems an important priority to empower patients to self-manage their diabetes (Poureslami, Nimmon, Rootman & Fitzgerald, 2016). Schillinger et al. (2002) conducted a study with low-income patients with diabetes and found that patient with limited health literacy were more prone to have a diabetes-related complication. They suggested that patients with limited health literacy reported micro- and macrovascular complications of diabetes such as retinopathy and cardiovascular disease. Another study found an association between heart failure in patients with diabetes who have limited health literacy (Laramee, Morris & Littenberg, 2007). However, a study conducted by Morris, MacLean and Littenberg (2006) did not find any statistically significant association between health literacy and diabetes-related complications. But the authors of this study recognised how the small sample size of patients with low health literacy might reduce the power to detect the significant results. Whereas Sarkar et al. (2010) found that limited health literacy associated with a higher risk of hypoglycaemia in insulin-treated patients with diabetes. The research evidence so far, considered, improving health literacy can improve health outcomes for people living with diabetes. Interventions that can be utilised to improve health literacy and diabetes outcomes are discussed in the next section.

3.7.3   Interventions to improve health literacy and diabetes outcomes

According to Nutbeam (2000), health literacy is the outcome of health education and health promotion. He described the educational intervention to improve health literacy according to the typology presented in Chapter 2 Section 2.1 (p.13). *Firstly*, the goal of using education to improve functional health literacy through factual information on health

and the access and utilisation of health care services. This information can be transmitted through existing channels, from other people and media resources. *Secondly,* the goal of developing communicative health literacy is the development of personal skills in a supportive environment. These skills developed through tailored health communication to specific needs, facilitating self-help and social support group, and enhance a combination of different channels for communication. *Finally,* the goal of improving critical health literacy is to facilitate individual and community empowerment through provision of information on the social and economic determinant of health and opportunities to achieve policy and organisational change.

Improved health literacy on the three levels discussed above has the benefit of having improved knowledge along with the capacity to act independently on knowledge, improved motivation and self-confidence. It will also improve resilience to social and economic adversity, while it can have the benefits at the community level too and can build the capacity to act on social and economic determinants of health and can enhance community empowerment (Nutbeam, 2000).

However, educational strategies aiming at increasing critical health literacy are essential as they involve more than the just transmission of health information and consider wider social and economic determinants to promote policy and organisational change in the community (Wang, 2000). So in the case of diabetes management, it goes beyond the development of the self-management skills in the people from the South Asian community, as there are so many cultural and societal barriers that hinder the development of health literacy skills in the ethnic minorities that need to be considered in developing an intervention plan for any specific community. In this research, the aim is to focus on the wider social perspective to study health literacy based on the asset approach as discussed in Chapter 2, Section 2.2 (p. 18).

Education is considered to be a fundamental part of diabetes care, and there are some educational strategies that have been used to improve diabetes self-management. Educational interventions for diabetes are complex and varied in nature, that should be evidenced based and meet the needs of the individual (Ghosh & Collier, 2012). Within the broader spectrum of educational interventions for people with diabetes and other chronic medical conditions, there are specific self-management educational programs available (traditional patient education provides information and technical skills while self-management education teaches problem-solving skills). Self-management education takes place in the realm of patient education that improves problem-solving skills of patients to enhance their lives and compliment with patients education rather than a substitute for traditional patient education (Bodenheimer et al., 2002).

There have been specific programs for diabetes, for example, Diabetes Education and Self-management for Ongoing and Newly Diagnosed (DESMOND) and Dose Adjustment for Normal Eating (DAFNE) which have been developed for people with type 2 and type1 diabetes respectively. DESMOND is a collaborative name for a family of group self-management education modules, toolkits and care pathways for people with, or at higher risk of type 2 diabetes (NHS, 2016). DAFNE is a way of managing type1 diabetes, and it provides the skills necessary to estimate the carbohydrate in each meal and to inject the right dose of insulin. It has been recommended by the NHS and The National Institute for Health and Care Excellence (NICE) to provide educational courses as part of their diabetes service (Coulter & Ellis, 2006). The importance of culturally appropriate care for diabetes, DESMOND the structured education program is available specifically for people from the South Asian community living with diabetes (NHS, 2015).

Apart from the traditional educational interventions, extensive informational networks, emotional networks, and attendance at community organisation were linked to

better self-management capabilities especially people with low education. Access to information support networks may equip an individual to have information available from more than one source and provide the opportunity to compare and choose the best-suited information according to their individualistic situation. Strong social and informational support may compensate for the adverse impact of low education at least on self-management capabilities of diabetes patients (Koetsenruijter et al., 2016).

Overall, the aim of the interventions to improve health literacy and diabetes management is the development of the abilities and capacities that can empower the individuals in taking control of their lives. It also considers bringing system based changes that enable each individual to access and utilise the healthcare information and services according to their needs. Further improved health literacy can improve self-efficacy to take practical actions as a part of diabetes management. All these factors together can help the individual to have a good quality of life while living with diabetes. Next, the concepts of empowerment, self-efficacy and quality of life about diabetes management and health literacy will be presented.

3.8 Empowerment

Empowerment is a construct shared by many discipline and areas including psychology, community development, education, economics and studies of social movements and organisation. Similar to the concept of health literacy there are many definitions of empowerment. The concept of empowerment varies from researcher to researcher and within the context where it is being used (Wallerstein & Bernstein, 1988). In its most general sense empowerment refers to " the ability of people to gain understanding and control over personal, social, economic and political forces to take action to improve their life situations" (Israel, Checkoway, Schulz & Zimmerman, 1994, p. 152). The concept

'empowerment' has derived from the work of the Brazilian educator, Paulo Freire (1970). He developed a strategy to teach critical consciousness to the underprivileged people of Brazil. Freire's approach proposed a dialogue in which everyone participates as co-learner, and at an equal level to have a critical reflection upon the root causes of the problems they identified and to look for their possible solution (Freire, 1970).

In recent years there has been an increased need for empowerment for patients and healthcare professionals in the healthcare context (Meetoo & Gopaul, 2005) therefore the concept of empowerment has become more popular in a healthcare context (Wallerstein & Bernstein, 1988).

In the healthcare contexts empowerment has been described as an absence or decline of powerlessness, alienation, helplessness, oppression, subordination, and paternalism (Gibson, 1991). Empowered patients are considered to have a greater control of their health and shared healthcare processes with health care professionals (Roberts, 1999). Freire's (1970) ideas about empowerment have been utilised in the field of health education to form the theoretical basis for the development of health education strategies. The purpose of health education is to "provide a combination of knowledge, skills, and a heightened self-awareness regarding values and needs, so that patients can define and achieve their goals" (Feste & Anderson, 1995, p. 140). These beliefs constitute the philosophy of patient empowerment. Moreover, empowerment can be viewed either as a process or as an outcome (Gibson, 1991) in a broader sense, empowerment is a process by which people, organizations and communities gain mastery over their life (Rappaport, 1984), by acting on issues that they define as important (Page & Czuba, 1999) that runs alongside patient education and at the same time it can also be an outcome of patient education (Anderson & Funnell, 2010).

The patient empowerment paradigm considers the patient as an expert, similar in importance to the expertise of the healthcare professionals. Patients accept the responsibility to manage their conditions and are encouraged to solve their problems with the information, but not with orders, from professionals (Funnell & Anderson, 2003). Within the philosophy of empowerment, the role of health care professionals or educators is not to change patients' behaviours but to inspire, inform, support, and facilitate their efforts to identify and attain their goals (Funnell & Anderson, 2004). In this paradigm, internal motivation is considered more effective than an external source of motivation in bringing lifestyle changes (Bodenheimer et al., 2002). People are empowered when they have sufficient knowledge to make rational decisions, sufficient control and resources to implement their decisions and sufficient experience to evaluate the effectiveness of those choices (Funnell & Anderson, 2003).

According to Nutbeam (1998), effective use of health information is critical to empowerment. Health literacy is fundamental to patient engagement and empowerment if individuals do not have the capacity to obtain, process and understand basic health information, then they will not be able to look after themselves effectively or make appropriate health decisions (Coulter & Ellins, 2007). People with limited health literacy may have limited knowledge and understanding that can prevent them to be autonomous in taking decisions about their health. This makes them more vulnerable to be in control of others because of their limited ability to understand what they are reading and what has been said to them. Further, this can result in a lack of patient-provider communication that also hinders the shared decision-making process. If the health care professionals do not recognise the health literacy needs of the patients this can result in poor health outcomes.

Limited health literacy raises the ethical concern of power between health care providers and receivers, as patients with limited health literacy can feel oppressed, and this

can be more problematic for the people who speak a different language from the health care professionals (ethnic minorities) (Erlen, 2004). Although there is still debate about the rights of patients to choose whether or not to act according to treatment regimes this can be hugely determined by the patient's knowledge and understanding of health (Beauchamp & Childress, 1994). Thus for the people with limited health literacy faced with difficulties to take informed decisions and will feel less empowered. However, the recent definition of health literacy goes beyond the personal characteristics and consideration of community resources also play an important role in using health information in making decisions about health.

Consideration of the wider physical and social environment and an examination of attitudes, places and practices within the health care system are necessary to achieve control over health (Minkler, 1989). Gibson (1991) further relates this concept with empowerment, which not only captures the individual responsibility in achieving health but also the effects of the social environment on personal health. The development of self-management skills and improving health literacy at the individual level can empower the individual to take control of their health. But it also suggests promotion of health may have more to do with ensuring the preconditions for individual self-management responsibility are met than merely focusing on the individual level. An education approach that reveals the resources along with considering the limitation within and without patient can be a potential method to empower the patients to take control of their health. The consciousness raising in the patient's actual situation is a way to make a change and ensure that the power comes from the patient themselves. This conscious raising is the goal of the theory presented by Paulo Freire, focusing upon the critical reflection on reality and the mutual dialogue process as a part of bringing change in the society (Hage & Lorensen, 2005).

The Marmot Review (2010) highlighted the need for empowerment of individuals and community in reducing health inequalities in society. Individual empowerment needs social actions, thus there is also a need to create social change in the environment. At the community level, there is a need to remove the organisational barriers that influenced access and utilisation of health services and on the other hand, build capacity and capability in individuals through personal and community development interventions. In this regard, Paulo Freire's democratic and liberty vision of education is important to consider, emphasising the oppressed group's active participation in their education and in taking control of their lives (Rudd & Comings, 1994).

A goal of patient empowerment is to improve adherence to an agreed self-management regime, as people with diabetes are often unsure as to whether they can achieve their set goals. From the perspective of diabetes patients, then need information, assurance, support and care to become empowered. People with diabetes can be empowered through the knowledge, skills, attitudes and self-awareness necessary to influence their behaviour to improve the quality of their lives. Provision of diabetes education will allow the patients to have the information and skills they need to attain mastery over their diabetes care (Funnell & Anderson, 2003). It can give rise to the number of well-informed patients who want to learn about the care and education they should receive and be aware about their rights as a patient (Meetoo & Gopaul, 2005). Personal awareness and supportive environment will enable individuals to set the realistic goals and to have a belief to carry on the actions as part of self-management of diabetes.

3.9   Self-efficacy

Self-efficacy is an important psychological construct, and it entails a person's confidence in performing a desired task or behaviour (Bandura, 1977). Self-efficacy holds the belief

that achievement of the action plan is more important than the plan itself (Bodenheimer et al., 2002). The concept of self-efficacy is based on Bandura's social cognitive theory and has been defined as a person's belief in their ability to succeed in a particular situation. Self-efficacy beliefs determine how a person feels, thinks, motivate themselves and behaves. People with high self-efficacy approach difficult tasks as a challenge to be mastered rather than as a threat to be avoided (Bandura, 1994).

In the healthcare context, self-efficacy may entail a patient's confidence in their ability to perform health behaviours (Bandura, 1977) and predicts self-management for patients with a number of chronic illnesses (Jahanlou & Karami, 2009; Inoue & Takahashi & Kai, 2013) across the literacy levels (Gerber et al., 2005). Self-efficacy refers to an individual's belief in their capacity to successfully learn and perform a specific behaviour. A strong sense of self-efficacy leads to a feeling of control, and willingness to take on and persist with new and difficult tasks. When applied to health, this theory suggests that patients are empowered and motivated to manage their health problems when they feel confident in their ability to achieve this goal (Coulter & Ellins, 2006).

As mentioned earlier, self-efficacy is informed by the social cognitive theory which emphasises the interaction of personal factors (i.e. beliefs and cognitions) and environmental factors (physical and social) shape or influence behaviour of an individual. Social cognitive theory illustrates that self-management of chronic illnesses do not occur in a vacuum but rather in a context that includes formal health care providers, informational social network, and the physical environment. All these factors influence the self-management behaviour either directly or indirectly through self-efficacy (Gallant, 2003). How people think and feel about their condition can have a big impact on their health behaviours and outcomes (Padilha, 2010; Lubetkin, Lu & Gold, 2010; Shigaki et al., 2010). Higher self-efficacy is associated with improved health behaviours and clinical

outcomes (Remmers, Hibbard, Mosen, Wagenfeld, Hoye & Jones, 2009; Greenfield, Kaplan & Ware, 1985; Song, 2010; Weng, Dai, Huang & Chiang, 2010; King et al., 2010). Studies also suggest that self-management support that includes behaviour change strategies and problem-solving skills are more likely to lead to improved self-efficacy and lifestyle modification (Bourbeau, Nault & Dang-Tan, 2004; Glasgow, Toobert, Barrera & Strycker, 2004).

Understanding the mechanism through which self-efficacy can influence the different quality of life outcomes and how it is related to health literacy could be relevant to self-care and chronic disease management (Rak, 2014). Previous studies exploring the relationship between health literacy, self-efficacy and glycemic control have shown mixed results (DeWalt et al., 2007; Ishikawa et al., 2008; Sarkar et al., 2006). Cavanaugh and colleagues (2008), reported a relationship between diabetes self-efficacy and diabetes-related numeracy.

Another study (Osborn et al., 2010) also demonstrated that health literacy and numeracy skills are associated with greater diabetes self-efficacy, and diabetes self-efficacy is associated with glycemic control. It was also mentioned in this study that numeracy related skills are more strongly associated with diabetes self-efficacy than health literacy (Osborn et al., 2010). These findings highlight the need to consider self-efficacy as an important target as part of diabetes educational interventions, particularly for the people with limited health literacy and numeracy skills.

Research has demonstrated mixed results for interventions in diabetes that attempt to improve self-management behaviour through improved self-efficacy (Glasgow et al., 2001) and particularly little is known about the race and ethnic explanation about self-efficacy and diabetes management in people with different health literacy levels. People

from the South Asian community in the UK tend to have limited health literacy (Estacio et al., 2012) and improving self-efficacy may act as relevant determinant of self-management behaviours in this population (Kim et al., 2004; Sarkar et al., 2006) that can improve quality of life while living with diabetes.

3.10 Quality of life

The quality of life is viewed as a broad and multidimensional construct that encompasses several life domains (Livneh, 2015). Its core domains include physical and psychological well-being, social and interpersonal well-being, financial and material well-being, employment or productivity and functional ability (Bishop, 2005). The World Health Organization (WHO) defines quality of life as "individual's perception of their position in life in the context of culture and values system in which they live and to their goals, expectations, standards and concern" (WHO, 1998, p. 3). In the medical domain, it denominates aspects of health from the patient's or subject's point of view, and could better be expressed as subjective health or functional status and well-being (Wandell, 2005).

People with chronic medical conditions such as diabetes have to face many problems which may impact on their quality of life. Also, they are often accompanied by other chronic diseases that require regular visits to several health care professionals, utilisation of services of clinics, and outpatient centres, patients' education and technical devices as part of the self-management. Supporting self-management can improve quality of life (Cedraschi et al., 2004; Wattana, Srisuphan, Parthiban & Upchurch, 2007; Smith, Nicholson & Banks, 2010). Research has indicated an association between self-management education, self-care behaviours and psychological outcomes, stress, coping or quality of life (Didjurgeit, Kruse, Schmitz, Stuckenschneider & Sawicki, 2002; Furmark et al., 2009; Cochran & Conn, 2008). Supporting self-management improves self-confidence

to self-manage and improved quality of life, while self-efficacy and improved control are correlated with improved quality of life (Heitkemper et al., 2004; Tang, Funnell, Brown & Kurlander, 2010; Clark et al., 2010).

Most studies reported that quality of life among people with diabetes is worse than the quality of life in the general population (Rubin & Peyrot, 1999). Although there is substantial research evidence available about the impact of diabetes on quality of life (Jahanlou & Karami, 2009), there is little research evidence available about the level of health literacy and quality of life with diabetes (Bailey et al., 2014) in the perspective of minority ethnic communities in the UK. Glycemic control is associated with better quality of life (Rubin & Peyrot, 1999) and with adequate level of health literacy (Rak, 2014). Self-efficacy is considered a predictor of better quality of life in individuals with diabetes. In this study, we sought to explore and examine health literacy, self-efficacy and quality of life in people with diabetes belonged to the South Asian community in the UK.

3.11 Summary

Health literacy in the context of diabetes management includes a constellation of skills that are critical to patients in managing their condition and navigating healthcare services. People with higher health literacy have better knowledge of diabetes (Kim et al., 2004) and inculcate better self-management (Powell et al., 2007).

In the healthcare process, it can affect the patient-provider communication to have shared decision making and have a choice of informed options according to their condition. Health literacy in people with diabetes can be improved through educational interventions that aim to improve health literacy, self-management of diabetes to empower the patients and increase control over their life and diabetes. Individuals with improved health literacy

can have more confidence in their skills and capacities that increase their level of self-efficacy to overcome the obstacles in the self-management of diabetes. Improved health literacy can improve the diabetes self-management process and reduce diabetes-related complications and can lead to having a better quality of life while living with this condition.

4 Research Framework and Methodology

4.1 Introduction

In general, there are three approaches to research having been identified: quantitative, qualitative and mixed methods (Creswell, 2014). This chapter briefly discusses the characteristics of each of these approaches and examined its underlying theoretical principles to help identify the appropriate methodological strategies that can be used to achieve the aims of this PhD.

4.2 What is quantitative methodology?

A quantitative methodology is a research approach where quantifiable properties of a given phenomenon are measured and analysed. Quantitative methodology strives for objectivity, replicability, and control with the aim of causal explanation and generalisation. Creswell (2014) defines quantitative methodology:

> "Quantitative methodology is a means for testing objective theories by examining the relationship among variables. These variables can be measured, typically on instruments, so that numbered data can be analysed using statistical procedures. The final report has set structure consisting of introduction, literature and theory, methods, results, and discussion" (p. 4).

Quantitative methods can be traced back to the empiricist, hypothetico-deductive, and positivist schools of thought. Empiricism refers to the theory of knowledge which suggests that knowledge can only be gained through our sensory experiences of the world (Sarantakos, 2013). Empiricist approach also believes that purely theoretical work cannot make us closer to the truth (Willig, 2008). Within this position emphasis on sensory

observation and measurement in the knowledge-generation process are fundamental components of quantitative methods.

Hypothetical-deductivism refers to the method of investigation which emphasises hypothesis building and testing in the formulation of scientific inquiry. It is considered the top-down approach, it begins with the formulation of hypothesis based upon theory/theories, tested through empirical means and thus data/observation suggests verification or falsification of the hypothesis (Bryman, 2012). A hypothetico-deductive approach is a circular approach used in quantitative research. Thus this process never proves or disapproves a hypothesis; it only refines it, which increases its validity and reliability over time.

Positivism was underpinned by the belief that reality is independent of us. The goal is the discovery of the theories, based on the empirical research (i.e. observation, experiments) (Collis & Hussey, 2014). As positivists believe reality is independent of us, they assume the act of investigating social reality has no effect on that reality (Creswell, 2014). Since it is assumed that social phenomena can be measured, positivism is associated with quantitative methods of analysis based on the statistical analysis of the quantitative research data (Collis & Hussey, 2014).

Later the criticism on naive realist assumption of positivism leads towards the development of post-positivism. It recognises the fact that it is not possible to be certain about our claim of knowledge when studying human behaviours, actions and accept that the natural sciences do not provide the model for all social research. However, they (post-positivists) do believe in the possibility of an objective reality that should be considered probable truths and can be used to predict future occurrence of the phenomena under investigation (Creswell, 2014).

In summarising the concepts mentioned previously of philosophical underpinnings of a quantitative approach, it can be summed up in three points: ontology, epistemology and methodology.

- The *ontological assumption* is concerned with the nature of reality, and positivist believes reality is objective and external to the researcher. Therefore there is only one reality, and everyone has the same sense of reality.

- *The epistemological assumption* is concerned with what we accept as valid knowledge. This involves an examination of the relationship between the researcher and that which is researched. Positivists believe that only phenomena that are observable and measurable can only be validly regarded as knowledge. They try to maintain an independent and objective stance.

- *The methodological assumption* in quantitative research is the need to operationalize the concept you want to measure and described in such a way that it can be measured. There is need to have a large sample, to focus on objective facts and formulate a hypothesis. The analysis will focus upon to look for any association between variables or causality (Collis & Hussey, 2014).

4.2.1 Critical evaluation of quantitative methodology

Quantitative research has many advantages in the use of research; it provides estimates of populations at large, provides precise definitive, and standardised levels of measurement. It also focuses on objectivity and accuracy of the results. It employs prescribed procedures to ensure validity and reliability along with avoiding personal biases by keeping a distance from the subjects by using computational techniques in interpreting the results (Punch, 2005). However quantitative methodology has been criticised due to its limitations.

Quantitative methodology perceives reality as objective, simple and fixed. Which has been criticised as reality is considered the interpretation of social actions and it cannot be the same for everyone (Punch, 2005). Strict research design can also limit the options for the research process. Inhibiting the initiative and motivation of the researcher as well can produce artificial results that may not reflect reality (Sarantakos, 2013). Further quantitative research is better to predict the cause and effect relationship between the variables and the reliance on the instruments (Creswell, 2014). Strict procedures might hinder the connection between research and everyday life (Bryman, 2012). This would not allow having an in-depth explanation of the understudy phenomena (Creswell, 2014). As positivists take the view that 'reality is out there', it is the job of the researcher to use the objective standard research methods to uncover the truth. However, in social sciences, this complete detachment and objectivity are somehow problematic due to part of the world that we are observing makes it difficult to overcome this. Quantitative methods have also been criticised because of it hypotheticodeductive approach to research. Hypothesis framed at the beginning of the research can direct the research process and as a result, limit the research options close to the intention of the researcher. In this way, a researcher can have power and control over the subjects (Sarantakos, 2013). The limitation of this approach leads towards the development of another approach that can address the issues raised on the quantitative methodology 'qualitative methodology'.

4.3   What is qualitative methodology?

The word qualitative implies an emphasis on the qualities of entities and on processes and meanings that are not experimentally measured or examined (Creswell, 1994). Qualitative research focuses on the socially constructed nature of reality, the intimate relationship

between researcher and what is being studied and the social constraints that shape inquiry (Denzin & Lincoln, 2000).

Denzin and Lincoln (2011) broadly define qualitative research as:

> Qualitative research is a situated activity that locates the observer in the world. Qualitative research consists of the set of interpretive, material practices that make the world visible. These practices transform the world. They turn the world into a series of representations, including field notes, interviews, conversations, photographs, recordings and memos to the self. At this level, qualitative research involves an interpretive, naturalistic approach to the world. This means that qualitative researchers studies things in their natural settings, attempting to make sense of, or interpret phenomena regarding the meaning of what people bring to them" (p. 3).

From the definition stated above, it is understood that qualitative research embraces the philosophical assumptions that values participants own interpretation of reality and, therefore assumes that reality is socially constructed by individuals within their context. Qualitative research, therefore, focuses on to study the participants in their natural settings and interact with them in their language and also rejects nomological thinking and the notion of research as being value-free. It also emphasises the active role of the researcher in the research process as opposed to the passive, detached observer in the quantitative paradigm. Table 4.1 (p.125) summarises the perceived differences in quantitative and qualitative methodology.

Table 4.1: Perceived differences between quantitative and qualitative methodologies
(Sarantakos, 2013, p.48)

Features	*Quantitative methodology*	*Qualitative methodology*
Nature of reality	Objective, simple, single, tangible sense impressions	Subjective; problematic; holistic; a social construct
Causes and effects	Nomological thinking; cause-effect linkages	Non-deterministic; mutual shaping; no causal effect linkage
The role of values	Value neutral; value-free inquiry	Normativism; value bound inquiry
Natural and social sciences	Deductive; model of natural sciences; nomothetic, based on strict rules	Natural and sciences are different; inductive; idiographic; no strict rules; interpretations
Methods	Quantitative, mathematical, extensive use of statistics	Qualitative, with less emphasis on statistics; verbal and qualitative analysis
Researcher's role	Passive, distant from the subject: dualism	Active; 'knower' and 'known' are interactive and inseparable
Generalisation	Inductive generalisation nomothetic statements	Analytical or conceptual generalisation; time and context specific

There are different traditions in qualitative research, 1) the constructivist; 2) interpretative and 3) critical approach. Constructionism focuses on the firm belief that there is, in practice neither objective reality nor objective truth. On the contrary, reality is constructed. This means that reality is socially constructed and it is constructed differently by each individual (Castellan, 2010) based on the culturally defined and historically situated interpretations and personal experiences (Sarantakos, 2013). The process of construction and reconstruction are laden with personal inputs. The key process that facilitates construction and reconstruction is interpretation. In the qualitative research, interpretivism looks for culturally derived and historically situated interpretations of the

social life-world (Sarantakos, 2013). The critical paradigm comprises a set of alternative basic beliefs that may trace back to critical theory (Gelo, 2012). The critical approach also takes reality as a social construct. However, in critical approach, the relevance of broader social context also considered important in the creation of reality and how this process is being influenced by the structure of power within the society. A critical approach is oriented towards criticising and changing the society as a whole (Calhoun, 1995) and concerned with equity and justice about issues such as race, religion, socioeconomic status (Kincheloe & McLaren, 2000). Critical evaluation for the qualitative research is discussed in the following section.

4.3.1 Critical evaluation of qualitative methodology

Qualitative research is considered an alternate way of being scientific with the aim of contextual (and eventually critically) understanding, subjective perspectives and experiences of the participants. It aims for in-depth and holistic understanding. To do justice to the complexity of social life (Punch, 2005) and to reconstruct the personal meaning and experiences conveyed by the participants (Gelo, 2012). Pre-structuring of designs and data is less common and its methods are less formalised than those in the quantitative approach (Punch, 2005). Qualitative research encourages the active involvement of the researcher and attempts to minimise the distance between the researcher and what is being researched (Willig & Stainton-Rogers, 2008). The researcher can be able to interact with the participants in their language and on their terms (shared research process) that can neutralise the notion of power and control of quantitative methodology.

Most of the limitations of the qualitative methodology also reflect their inherent strengths. The criticism of qualitative research can be attributed towards its deviation from the positivist stance of quantitative methodology. Due to the context-specific nature of qualitative research, a small number of sample sizes within a certain organisation or locality it is considered impossible to generalise the findings to other settings (Bryman, 2012). As it is flexible in nature, there might be a chance of drifting away from the original objectives of the study in response to the changing circumstances and context within which study has been conducted. Data collected through qualitative methods is considered time-consuming and require more resources including a high level of expertise from the researcher to obtain the targeted information from the participants (Anderson, 2010).

Ethics can also be a concern in qualitative research as in qualitative methodology the research process allows the close contact with the respondents and particularly when the aim is to explore any sensitive issue (Sarantakos, 2011). Concerns over the invasion of personal life, and lack of transparency over research process are also considered further limitations in the qualitative methodology (Bryman, 2004). The common points of criticism on qualitative research (i.e. less structured approach, in-depth exploration, small sample size) are considered as strengths of qualitative methodologies as these were the philosophical underpinnings that give rise to a qualitative approach. However concerns over reliability and validity are considered and addressed differently within qualitative research from those employed in quantitative research (Sarantakos, 2011). The perceived advantages and disadvantages of both qualitative and quantitative research give rise to the third paradigm that emphasis on to combine both approaches in order to compensate the merits and demerits of both in order to achieve the research aims.

4.4 Combining multiple methodologies

The incommensurability thesis between quantitative and qualitative research creates a dilemma for researchers who use both (qualitative and quantitative) methods in their research. In order to justify the application of multiple methods, the notion of triangulation as a superior approach was emerged (Symonds & Gorard, n.d). That was termed as mixed methods research, although before the advent of the mixed methods, many studies used multiple methods to achieve the benefits of triangulation without restricting themselves to any paradigmatic membership of methodological category (Tashakkori & Teddlie, 2003). According to Tashakkori and Tedidlie (1998) in 1978, Denzin applied the term triangulation that means to combine the data sources to study the same social phenomena. He described three types of data triangulation: 1) data triangulation (the use of variety of data sources in a study), 2) theory triangulation (the use of multiple perspectives to interpret the results of the study), and 3) methodological triangulation (the use of multiple methods to study a research problem) (Tashakkori & Teddlie, 1998).

The general advantages of mixed methods research (as well as its ability to reveal high quality and complex inferences) are cited as the reasons for the growing interest in mixed methods designs. The complexity of the research objectives, the inductive logic of qualitative inquiry and the utility of the mixed methods designs that allowed for meaningful combination of quantitative and qualitative methods in a single study seem to be the major factors that caused social, behavioural, and health sciences to embrace mixed methods research (Ivankova & Kawamura, 2010). In mixed methods research, the use of both quantitative and qualitative approaches in combination provides a better understanding of research problem than either approach alone (Creswell & Plano Clark, 2007). Combining the internal validity of the quantitative methods with the external

validity of the qualitative methods can thus be a very productive way of mixing methods (Yardley & Bishop, 2008). Mixed methods as a research approach is discussed in the following section.

4.5   What is mixed methods research?

Mixed methods research is defined as a combination of qualitative and quantitative research methods by a researcher or team of researchers that aimed to have breadth and depth of understanding of certain phenomena from a single study or closely related studies (Pluye, Gagnon, Griffiths & Johnson-Lafleur, 2009).

Creswell (2014) define mixed methods research:

> "Mixed methods research is an approach to an inquiry involving collecting
> both quantitative and qualitative data, integrating the two forms of data,
> and using distinct designs that may involve philosophical assumptions and
> theoretical frameworks. The core assumption of this form of inquiry is that
> the combination of qualitative and quantitative approaches provides a
> complete understanding of a research problem than either approach alone"
> (p. 4).

From a theoretical perspective, mixed methods research is premised on the idea that there are not only the multiple ways of making sense of the social world but also multiple standpoints on what is important and valuable. No single method is more superior either quantitative or qualitative rather using more than one approach can provide more insight towards understanding the complexity of social phenomena (Dures, Rumsey, Gleeson & Morris, 2010; Creswell & Plano Clark, 2007; Tashakkori & Teddlie, 2003). Philosophical

foundations that give rise to mixed methods research is 'pragmatism' discussed in the following section.

4.5.1   Philosophical foundations of mixed methods: Pragmatism

'Pragmatism' or 'philosophy of free choice' is the most appropriate epistemology for mixed methods, with the additional strength given by the adoption of pragmatism, mixed methods was recently claimed to be the third paradigm in a trinity of quantitative and qualitative approaches (Johnson & Onwuegbuzie, 2004). Pragmatists advocate that researchers should be free to mix methods from a different paradigm, choosing them on the usefulness of answering the research question(s). They suggest that by ignoring the philosophical debate about reality and nature of knowledge the weakness of one paradigm can be offset by the strength of another. The pragmatic approach is an attempt to cross the divide between the quantitative (positivist) and qualitative (non-positivist) and to utilise both approaches in search of reality (Collis & Hussey, 2014).

Tashakkori and Teddlie (1998) defined pragmatism:

> "Pragmatism is appealing (a) because it gives us a paradigm that philosophically embraces the use of mixed method and mixed model designs, (b) because it eschews the use of metaphysical concepts (truth, reality) that has caused much endless (and often useless) discussion and debate, and (c) because it presents a very practical and applied research philosophy: Study what interests you that have value to you, study it in different ways that you deem appropriate, and use the results in ways that can bring about positive consequences within your value system" (p. 30).

Pragmatism derives from the work of Peirce, James, Mead and Dewey. There are many forms of this philosophy, but for many, pragmatism as a worldview arises out of actions, situations, and consequences rather than antecedent conditions (as in post-positivism) (Creswell, 2014). Pragmatists consider practical consequences to be the vital component of the truth. Theories are true to differing degrees, based on how well they work at the time regarding applicability and feasibility (Dures et al., 2010). According to the pragmatic perspective, there is no fundamental contradiction between basic objectives and characteristics of qualitative/constructivist and quantitative/positivist research, even though the methods of inquiry and validation appropriate for each other are very different. However, while pragmatism may appear to offer a way to end the quantitative versus qualitative paradigm tensions, not everyone regards it as a convincing solution (Yardley & Bishop, 2008).

Pragmatism contends that the research question should determine the research philosophy and that methods from more than one paradigm can be used in the same study (Collis & Hussey, 2014). A pragmatic approach would concentrate on methodology as an area that connects issues at the abstract level of epistemology and the mechanical level of actual methods. Morgan (2007) has suggested several ways that pragmatism provides new options for addressing methodological issues in the social sciences:

- The distinction between inductive and deductive approaches is one of the key features that distinguish qualitative and quantitative research approaches. In pragmatic perspective, it is not possible to operate in either an exclusive theory or data-driven fashion during the research process. Thus pragmatic approach relies on a version of abductive reasoning that moves back and forth between induction and deduction like first converting observation into theories and then assessing those theories through actions.

- Another dichotomy between quantitative and qualitative research is the concept of subjectivity and objectivity between the researcher and the research process. It is hard to have complete objectivity or subjectivity in social sciences research, so the pragmatic approach focuses on the intersubjective approach that captures this duality.

- Another distinction between quantitative and qualitative approaches is the distinction between the knowledge that is either context specific or universal. Pragmatic approach rejects this extreme and suggests that an important question is an extent to which we can take the things that we learn with one type of method in one specific setting and make the most appropriate use of that knowledge in other circumstances.

Concepts of pragmatism presented by Howe (1988) considered qualitative and quantitative methods compatible, and that researchers can use both methods in their research process. Reichardt and Rallis (1994) have identified similarities between qualitative and quantitative methods that increase the nature of compatibility between both research approaches. These similarities in fundamental values include belief in the value-ladenness of inquiry, belief in the theory-ladenness of facts, belief that reality is multiple and constructed, belief in the fallibility of the knowledge, and belief in the under-determination of theory by fact (Reichardt & Rallis, 1994).

Instead of searching for metaphysical truth pragmatists consider truth to be ''what works'' (Tashakkori & Teddlie, 1998). Thus it can be argued that there is a common set of beliefs that many social and behavioural scientists have that undergird a paradigm distinct from positivism or post-positivism or constructivism, which has been labelled pragmatism. The paradigm allows for the use of mixed methods in social and behavioural research (Tashakkori & Teddlie, 1998). Instead of focusing on research methods, pragmatism focus

on the use of approaches to understanding the problem and considered as philosophical underpinnings for mixed methods research studies. Creswell (2014) Outline the following philosophical basis that pragmatism provides a basis of knowledge claims and how this fits with a mixed method approach:

- Pragmatism is not committed to any one particular philosophy; rather it focuses on the use of mixed methods research approach that gives liberty from both qualitative and quantitative assumption in the research process.

- Researchers are free to choose methods, techniques, procedures of research that best suit to look for an answer to their research questions.

- Pragmatists do not see the world as an absolute unity, in the same way, mixed method researchers use more than one approaches instead of sticking to one (quantitative or qualitative).

- In the pragmatist paradigm, truth is what works at the time. It is not based on the dual reality independent of the mind or within the mind, thus in mixed methods research, quantitative and qualitative methods are both utilised to gain a comprehensive understanding of the research problem.

- The pragmatists' research look to what and how a research based on the intended consequences where they want to go with it. In line with this assumption, mixed methods researchers need to establish a rationale why quantitative and qualitative research method needs to be mixed.

- Pragmatists agree that research always occurs in social, historical, political, and other contexts. In this way, mixed methods studies may include postmodern turn, a theoretical lens that is reflective of social justice and political aims.

According to all these philosophical, practical underpinnings of the pragmatic paradigm, it allows the mixed methods researchers to utilise multiple methods, different

worldviews, and different assumptions, as well as different forms of data collection and analysis (Creswell, 2014). As per diversity and complexity of the research areas, there is a wealth of mixed methods designs available that can be utilised to find the research questions. Mixed methods research designs are discussed in the following section.

4.5.2 Mixed methods designs

The mixed methods research design is selected on the purpose of the study, timings of qualitative and qualitative elements and emphasis on one element over the other. The selection of mixed methods designs determined by the researchers' reason of combining methods that may result in a classification based on the order in which quantitative and qualitative elements of the study are implemented. Another way to label the mixed methods is according to which element is emphasised. In this classification, the emphasised element will be mentioned in uppercase letters (QUAL or QUANT) and the other in lower case font (qual or quant). There have been several typologies for classifying and identifying types of mixed methods strategies that researchers can use in their proposed mixed methods studies. There are at least 15 typologies of mixed methods design that have been published (Creswell & Plano Clark, 2011). This proliferation is somehow daunting, particular for the new researchers (Bishop, 2005). In this section, for the simplicity of the discussion, this will be limited to the approaches usually implemented in health research and also consistent with three basic designs presented by Creswell. Creswell (2014) has described three basic strategies: 1) exploratory sequential mixed methods, 2) explanatory sequential mixed methods, and 3) convergent concurrent mixed methods.

4.5.2.1 Exploratory sequential mixed methods

The exploratory sequential designs begin with collection and analysis of qualitative data and the findings will be used to design the quantitative phase. In health psychology, it can be used to develop a new instrument, by conducting qualitative research to identify the relevant constructs and following this up with quantitative research of testing validity and reliability of the newly developed scale (Bishop, 2015). This design can also be used to collect data about patient's' perspective concerning an issue or problem, so their point of view is represented and incorporated in developing interventions. Qualitative findings can also generate hypotheses for quantitative research (Morgan, 2014). The use of both qualitative and quantitative methods allowed researchers to develop well-grounded research hypothesis and test them in the same study. The exploratory sequential mixed methods (see Figure 4.1) can also be used to study the area or topic which has not been studied before.

Figure 4.1: Exploratory sequential mixed methods (Creswell, 2014, p. 220)
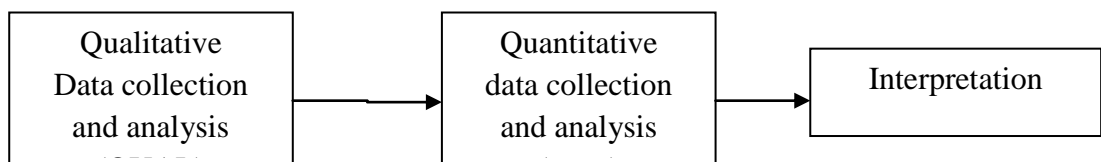
4.5.2.2 Explanatory sequential mixed methods

In explanatory sequential design, the researchers collect and analyse the quantitative data and then collect and analysed the qualitative data to explain and contextualise the earlier quantitative results (Creswell & Plano Clark, 2007). A qualitative examination of the phenomena facilitates the deep understanding is well suited to explaining and interpreting relationships. Explanatory sequential designs are easier to implement than other designs in

which qualitative and quantitative data collected at the same time. However, it also has some disadvantages as it requires more time and resources than would be needed for single method study. If the same participants will be part of the studies, it raises some ethical challenge as it is difficult to know what ethical challenges will appear in the subsequent qualitative study. This can be sorted out by obtaining consent to reconnect people and further amendments in the ethical protocol and their approval can be sought to overcome this issue (Bishop, 2005). Further published studies using this design are more difficult to identify in the literature because the two phases sometimes publish separately. Figure 4.2 demonstrates explanatory sequential mixed methods in which quantitative data (dominant approach) leads to qualitative data and further interpretations.

Figure 4.2 Explanatory sequential mixed methods (Creswell, 2014, p. 220)

```
┌──────────────────┐        ┌──────────────────┐        ┌──────────────────┐
│   Quantitative   │        │   Qualitative    │        │                  │
│ data collection  │ ─────> │ Data collection  │ ─────> │  Interpretation  │
│  and analysis    │        │  and analysis    │        │                  │
│     (QUAN)       │        │      (qual)      │        └──────────────────┘
└──────────────────┘        └──────────────────┘
```
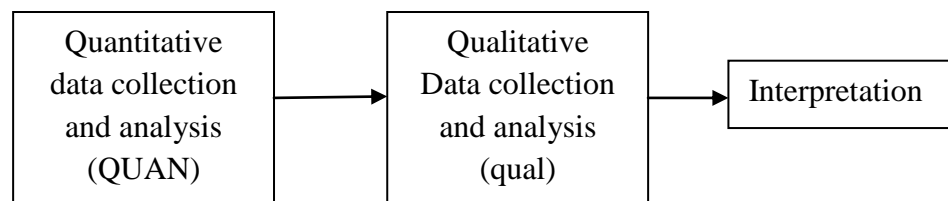
4.5.2.3 Convergent concurrent mixed methods

In convergent concurrent designs, researchers use quantitative and qualitative methods in an attempt to confirm, cross-validate, or support findings within a single study, using a single sample (Bishop, 2005). In this strategy both qualitative and quantitative methods are used separately to allow the strengths of two methods to complement each other. Therefore qualitative and quantitative data are collected concurrently. In convergent concurrent designs, integration of the results happens during interpretation the phase where convergence strengthens the knowledge claims, whereas the lack of convergence identifies

the areas for future research or theory development (Creswell & Plano Clark, 2007). Figure 4.3 illustrated the flow and direction of the convergent concurrent mixed methods.

Figure 4.3: Convergent concurrent mixed methods (Creswell, 2014, p. 220)
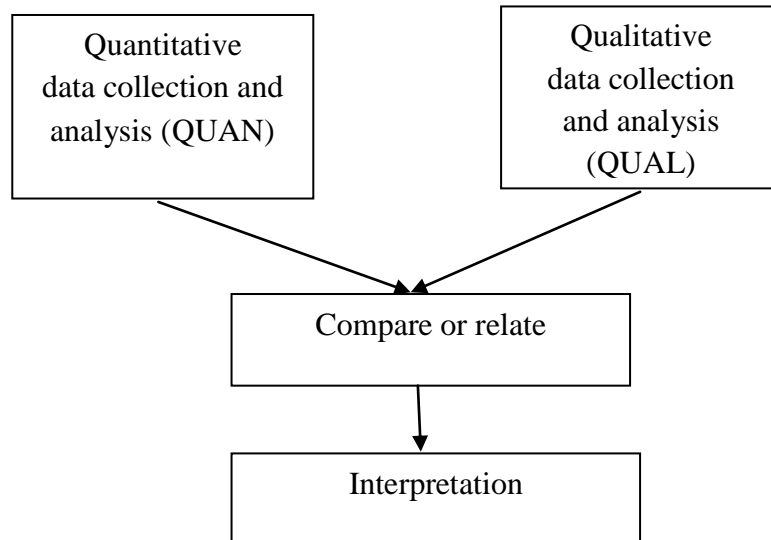
4.5.3 Critical evaluation of mixed methods

The ultimate goal of any research project is to answer the research question(s) that were set forth at the beginning of the project. Mixed methods are useful if they provide the answers to the research questions. There are three areas where mixed methods are superior to a single approach design:

- Mixed methods answer the research questions that the other methodologies cannot.
- Mixed methods research provides better (stronger) inferences.
- Mixed methods provide the opportunity for presenting a greater diversity of divergent views (Teddlie & Tashakkori, 2003).

The quality standards by which to appraise mixed methods designs continue to evolve (Creswell, 2015). Mixed methods research strategies require a depth and breadth of research knowledge, as well as a significant commitment of time for completion. It is

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critical to determine the method of integration of this data that will be displayed in tables, graphs, or matrices. The sequential method requires a long-term commitment, so this is not best-suited approach for the researchers who have a time constraint on completion of their research (e.g. completion of a degree) (Creswell, 2015). While additional time also highlights the need for additional resources (van Griensven, Moore & Hall, 2014).

There is limited guidance available concerning how to combine data that is collected using two different research approaches (Ostlund, Kidd, Wengstrom & Rowa-Dewar, 2011). According to pragmatic philosophical basis, the motivation for the study and the desired outcome determines the best way to integrate the data of mixed method studies (Morgan, 2014). Depending upon the purpose of the study, presentation of findings can be accomplished using various types of graphs, tables and figures. Articulating a plan for data integration whether it is built upon from one phase to other. Expanding the view of the phenomena, or strengthening the findings with quantitative and qualitative findings. This plan can be adjusted during the study, but it can provide the structure necessary to complete the study (Creswell, 2015).

Yardley and Bishop (2015) discussed the challenges and benefits of using mixed methods in health research. They have raised the issue of training in mixing methods being comparatively rare, and that means researchers are not well-equipped to make a decision about how and when to integrate qualitative and quantitative research methodologies. There are some guidelines available in the literature about the integration of quantitative and qualitative methodologies during sampling, data collection, and data analysis (Sandelowski, 2000). However, the diversity of integration of qualitative and quantitative research methods makes it difficult to develop and apply specific criteria for mixing methods in mixed methods research (Yardley & Bishop, 2015). As discussed earlier it mainly depends on the research question(s) that determine when and where the mixed

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methods approach will be utilised. Next section demonstrated the mixed methods approach that has been utilised to achieve the aims of this research.

4.6   Rationale

The key research questions- what is the health literacy level? How can various factors have an influence on determining health literacy level? How people of South Asian community managing their diabetes? What are their health literacy needs? These research questions were addressed through a combination of two studies (Figure 4.4, p. 139).

Figure 4.4: Convergent concurrent mixed methods (Creswell, 2014, p. 220)

```
┌─────────────────────┐          ┌─────────────────────┐
│   QUAN (Survey)     │          │  QUAL (Photovoice)  │
│                     │          │                     │
│  Data collection and│          │  Data collection and│
│      analysis       │          │      analysis       │
└─────────────────────┘          └─────────────────────┘
             ↘                      ↙
           ┌──────────────────────────┐
           │    Compare or relate     │
           └──────────────────────────┘
                        ↓
           ┌──────────────────────────┐
           │     Interpretation       │
           └──────────────────────────┘
```
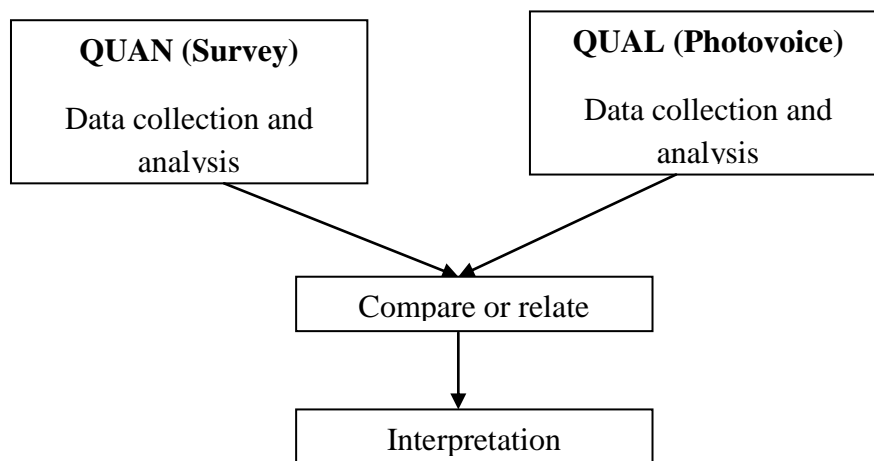
In study one quantitative method were used to show the distribution of health literacy level in this population and to analyse the relationship between variables and hence to identify those which are particularly significant, showing trends in larger population. In addition to quantitative methods, the question of 'how' is the central theme in this project. To answer the question of 'how participants are managing their diabetes?' 'What are their health literacy needs?' The qualitative approaches were used in study 2. Qualitative findings would facilitate to gain insight into the ways in which different dimensions of participants contexts, cultural needs and their experiences of using healthcare services

weave together in managing diabetes and in which way health literacy needs can be met for this specific group of population in the UK.

According to O'cathain, Murphy and Nicholl (2007), the use of mixed methods approach were usually grounded in the applied nature of health-related research which emanatined from a need to engage with the real world and address policy related issues in a complex research environment rather than any ideological stance. This is more a pragmatic issue to hear the voice of the service users and their experiences within the real world of managing diabetes and what can be done to improve their quality of life living with this condition. A comprehensive approach seems necessary due to the complexity of the issues under study. The experience of the participants' living with diabetes and cultural perspective are complex issues that need to utilise a qualitative approach to provide rich data for insider perspectives of this community.

4.7   Ethics

Ethical approval was obtained from Keele University Ethics Committee for both studies before data collection being carried out, and the ethical guidelines of the British Psychological Society (2009) were followed. All the participants provided informed consent before taking part in the studies and were advised they could withdraw at any time if they wish to. Data collected in study one (Survey) the response sheets were secured in the lockable cabinet at the Keele University. Data collected in the study two (Photovoice) was in the form of images and the verbal form. Images were also secured in the lockable cabinet while a soft copy of images and the verbal data also secured in lockable password computer at the Keele University. Anonymity was ensured where participants were quoted directly and cropping the images that showed any identity of the participants where images

being presented. Copies of the ethical approval letters can be found in the appendix (A & B).

4.8   Study one: Health literacy survey

4.8.1   What is survey research?

Survey research is common in studies of health and health services, although its roots lies in the social surveys conducted in Victorian Britain by social reforms to collect information on poverty and the working class (Kelley, Clark, Brown & Sitzia, 2003).

Today survey research is perhaps more commonly used a type of research design by applied researchers and practitioners. The term 'survey' used in a variety of ways but refers to the use of self-reported measures such as questionnaires and assessments as well as interviews, mainly used for collecting data on attitudes, beliefs, preferences, and behaviours from a representative sample of the population (Picardi & Masick, 2014). It can provide a snapshot of how things are at a specific time (Denscombe, 1998) and can be used for descriptive, comparative, and explanatory purposes (Picardi & Masick, 2014). Survey research can have potential benefits; it provides empirical data, findings can be generalised, and data can be produced in a short period with low cost. However, survey research does have its limitation, as data produced through survey lacks details or depth on the topic being studied. It can be difficult to have a high response rate from the respondents (Kelley et al., 2003). The use of survey in this research to study health literacy is presented in the following section.

4.8.2   The survey design

The purpose of this survey research was to show the distribution of health literacy level in the South Asians living in the UK and to analyse the relationship between variables. Hence

to identify those who were particularly significant, showing trends in the larger population. The design of the survey study allows a substantial number of participants to be recruited and a large amount of data to be collected that can be represented numerically (Fowler, 2014). The rationale behind using a quantitative study first was to establish the research evidence about the health literacy level in this ethnic minority group in the UK, as previous research has shown a particular concern for people belonging to ethnic minorities. Furthermore, as health literacy is not an individualistic concept it is shaped by the personal, social and economic factors, so that also was measured in this survey. This was a cross-sectional survey and data was collected at one point in time. The survey approach employs a range of methods to answer the research questions. Fowler (2014), had identified the following types of survey methods: mail, telephone, internet, personal interviews (face to face) or in a group setting. In the present study, face to face personal interviewing method was selected; there were certain reasons for doing it. To improve the response rate from the participants, the use of scales that needs self-administration (NVS-UK) and to minimise the English language barriers for the participants with limited English language proficiency.

4.8.3 The population sample

The population selected for this research were people belonging to the South Asian community living in the UK. The term South Asians broadly refers to the people belonging to India, Pakistan, Bangladesh, Nepal and Sri Lanka. However in this research the term South Asian represented the people belonged to Pakistani, Indian and Bangladeshi origins. People belonging to Pakistan, India and Bangladesh shared cultural and social traditions along with shared higher susceptibility to diabetes. According to Bowling (2002), it is impractical to collect data from each member of the population under study, and usually, a sample of the population has to be selected. In the present study purposive sampling was

used, as the focus was one particular group of people: South Asians. The main focus was on health literacy and diabetes management, but within the wider population people without diabetes were also recruited to establish the evidence about health literacy level in the general population. Sample one, the people with diabetes, were hard to recruit to reach the decided sample size for more powerful and statistically significant results. Participants with diabetes *(N=150)* and those from the wider community *(N=200)* were recruited for the study. There were 350 participants that ranged in age from 18-78, with a mean age of 34.82 (*SD=12.98*). Both females (46%) and males (54%) participated in the study.

4.8.4 Materials

A set of standardised questionnaires were administered as part of the process.

4.8.4.1 The European Health Literacy Scale-(HLS-EU-16)

This scale was developed by Sorensen et al. (2012) in a project to assess the health literacy in Europe. This is a content and context-specific measure of health literacy that covers three matrixes: health care, disease prevention, and health promotion. There are 16 items on this scale. The scale is based on the inverted categories of the items (i.e., higher value denotes better health literacy). The items were phrased as a direct question (not a statement). For example, 'on a scale from very easy to difficult, how easy would you say it is to......' perform a given health-related task.

Respondents rated their perceived difficulty on a 4-points Likert scale (very easy, easy, difficult, very difficult). An unsupported possibility was available for not answering the question, which was not offered by the interviewer but coded if the question was not answered. Scores on this scale reflect the health literacy level of the participants' 0-32

limited health literacy, 33-42 indicates sufficient health literacy and 43-50 is excellent health literacy.

The items of the HLS-EU-16 measure self-experienced and self-rated abilities to perform health relevant tasks of information management. The instrument does not just measure individual abilities or skills but the self-experienced and self-rated relation or fit to personal competencies and situational demands/complexities. Thus the measure reflects self-evaluated health literacy competencies about health literacy demands of specific contexts (in this case it is about health care system in the UK). A low level of health literacy in a certain country can be interpreted in different ways, either the country's population has specifically low competencies, or the health system is characterised by specifically high demands or a mixture of both (Sorensen et al, 2012). The current research focuses on both the perspectives of personal abilities and the complexities of the healthcare system. Furthermore, the interpretation of the results may also be influenced by the extent of experience of a given task, or by different rating tendencies (to rather understating or overstate difficulties) and by different expectations concerning difficulties of tasks (Appendix C).

4.8.4.2   Newest Vital Sign-UK-(NVS-UK)

The Newest Vital Sign (Rowlands, Khazaeizadeh, Oteng-Ntim, Seed, Barr & Weiss, 2013) is a standardised measure designed to assess individuals' functional health literacy skills in a quick and simple way. This measure conceptualises functional health literacy skills as the understanding and application of words (prose), numbers (numeracy), and forms (documents). The ability to read and analyse any nutrition label requires the same analytical and conceptual skills that are needed to understand and follow a provider's medical instructions.

In this test, the participant is given a specially designed ice cream nutrition label to review and is asked a series of questions about it. The participant can and should retain the nutrition label throughout the administration of the NVS. The participant can refer to the label as often as desired; there is no maximum time limit to answer the questions. The average time needed to complete all six questions is about three minutes. However, if a participant is still struggling with the first or second question after two or three minutes, the likelihood is that the participant has limited literacy and the assessment can be concluded. There is one point for each correct answer (maximum six points), and a score of 0-1 suggests high likelihood (50% or more) of limited functional health literacy, a score of 2-3 indicates the possibility of limited functional health literacy and score of 4-6 almost always indicates adequate functional health literacy. It shows higher internal consistency, Cronbach's alpha is 0.74 (Appendix D).

4.8.4.3 General Self-Efficacy Scale-(GSE)

The General Self-Efficacy Scale (GSE) (Schwarzer & Jerusalem, 1995), designed for age 12 years plus, was created to assess perceived self-efficacy regarding coping and adaptation abilities in both daily activities and isolated stressful events. It assesses the strength of an individual's belief in his or her own ability to respond to novel or difficult situations and deal with any associated obstacles or setbacks. GSE is a self-administered scale which normally takes two to three minutes to complete. Respondents are required to indicate the extent to which each statement applies to them. For each item, there is a four choice response from 'not at all true' which scores one to 'exactly true' which scores four. There are ten items in this scale, and total range of score is 10-40. The score for each of the 10 items is summed to give a total score. The score on this scale reflects the strength of an individual's generalised self-efficacy belief. Thus the higher the score, the greater the

individual's generalised sense of self-efficacy. It shows higher internal consistency in different samples, Cronbach's alpha ranged from 0.82 to 0.93 (Appendix E).

4.8.4.4   Diabetes Empowerment Scale-Short Form-(DES-SF)

The Diabetes Empowerment Scale (DES-SF) (Anderson, Funnell., Fitzgerald & Marrero, 2000) is a measure of psychosocial self-efficacy of people with diabetes. It measures the following aspects of self-efficacy of the individual with diabetes:

i) Managing the psychosocial aspects of diabetes: This aspect assesses individual's perceived ability to obtain social support, manage stress, be self-motivating, and make diabetes-related decisions that are "right for me."

ii) Assessing dissatisfaction and readiness to change: This aspect assesses individual's perceived ability to identify aspects of caring for diabetes that, they are dissatisfied with and their ability to determine when they are ready to change their diabetes self-management plan.

iii) Setting and achieving diabetes goals: This aspect assesses individual's perceived ability to set realistic diabetes goals and reach them by overcoming the barrier to achieving their goals (Anderson, Funnell, Fitzgerald & Marrero, 2000).

There are eight items in this scale. The scoring of the DES-SF is straightforward and is based on completed items. An item checked "strongly agree" receives 5 points; "agree" – 4 points; "neutral" – 3 points; "disagree" – 2 points; and "strongly disagree" receives 1 point. An overall score for the DES-SF can be calculated by adding all of the item scores and dividing by a total number of items in the scale. Reliability for DES-SF is 0.85 (Appendix F).

4.8.4.5 Audit of Diabetes-Dependent Quality of Life-(ADDQoL)

The Audit of Diabetes-Dependent Quality of Life (ADDQoL) was developed by Bradley (1994). It is an individualised instrument to measure individual's perception of the impact of diabetes on different aspects of their quality of life and overall quality of life of the individual. It assesses the quality of life on the following aspects:

i) which aspects of life apply to them and which do not

ii) the impact of diabetes on that aspect of life and whether that is positive or negative

iii) the perceived importance of each aspect of their life on the quality of life.

The ADDQoL consists of two overview items: present generic quality of life and diabetes-specific impact on quality of life. It is designed for use with adults or older adolescents with type1 and type 2 diabetes. Respondents rate the impact of diabetes on applicable domains (part 'a' of an item) on a scale from -3 (maximum negative impact) to +3 (maximum positive impact). Respondents then rate the importance of those domains for their quality of life (part 'b' of an item) on a scale from 3 (very important) to 0 (not important at all). Impact ratings are multiplied by the corresponding importance rating to provide a weighted impact score for each domain from -9 (maximum negative impact) to +9 (maximum positive impact). The weighted impact score is totalled and divided by the number of applicable domains, to give an overall Average Weighted Impact (AWI) score. The ADDQoL 18 shows higher internal consistency and the Cronbach alpha is .80 (Appendix G).

4.8.4.6 Demographics and lifestyle

After completing the questionnaires the participants were also asked to provide demographic data (e.g. gender, age, employment, qualifications, housing, income), and further questions about perceived health status (1 item), social capital (2 items), lifestyle, (5 items: general, diet, smoking, alcohol, physical activity) (Appendix H).

4.8.5 Procedure

Participants took part on an entirely voluntary basis and did not receive any monetary compensation. Participants were recruited via local South Asian Community groups using posters and word of mouth. Local schools and colleges were also visited, and posters (Appendix I & J) put on the notice boards to create awareness about the present research. Posters were also displayed on local market shops (South Asians) to raise awareness about the study after obtaining permissions from the shop owners.

Participants were informed about the purpose of the study before data collection. The researcher read the information sheet (Appendix K & L), cover sheet (Appendix M) and the questionnaire to the participants, so those who may have limited literacy skills do not feel obliged to do so. All the participants asked to provide informed consent before taking part. Questions were asked using the questionnaires that include health literacy-EU scale, functional health literacy scale (NVS-UK), self-efficacy and quality of life scale along with demographics and lifestyle questions.

Participants were assured for the confidentiality of their responses, that their responses would be anonymous by giving a number to their response sheet and assured that data would be used only for research purposes. It was ensured that participants understood

the nature and purpose of the research and further contact details were also provided for them to contact someone about anything related to this research project and its outcomes.

4.8.6 Data analysis

The demographics of the sample and their health status, health-related behaviours, along with the distribution of health literacy levels were identified using descriptive statistics. Relationships were then explored using different statistical analysis techniques: as much of the data was categorical, Chi-square tests of independence were used to explore possible differences between categories. Cell count should be five or more in 80% of cells to avoid violating assumptions (Pallant, 2010) were considered. Effect size in the Chi-square test for 2x2 tables used Cohen's criteria (1988) of *phi*=.10 for a small effect, .30 for a medium effect and .50 for a large effect. For larger tables, Cramer's *V* is reported, and effect size follows the guidelines in Pallant (2010) to take the smaller of (n_{row} categories-1) or (n_{column} categories -1), with values shown in Table 4.2.

Table 4.2: Cramer's *V* effect values

C – 1or R -1 Select smaller value	*V*: small effect	*V*: medium effect	*V*: large effect
1	.01	.30	.50
2	.07	.21	.35
3	.06	.17	.29

Correlational analysis was used to explore the relationship between health literacy, functional health literacy, self-efficacy, and perceived health status in the participants from the wider community. In the sample of participants with diabetes, the correlational analysis was carried out between health literacy, functional health literacy, self-efficacy and quality of life. For carrying out the correlation analysis, continues scoring was done of the health

literacy scales used in survey (health literacy, functional health literacy) to meet the assumptions of correlation analysis. Correlation analysis described the strength and direction of the linear relationship between variables. To determine the strength of the relationship of correlation results Cohen's criteria (1988) of $r=.10$ for a small effect, .30 for medium and .50 for large effect was used.

A logistic regression analysis was conducted to predict health literacy levels among participants. Logistic regression allows testing models to predict categorical outcomes with two or more categories. Predictor variables can be either categorical or continuous, or a mix of both in one model (Pallant, 2010). In the present research for logistic regression health literacy and functional health literacy was categorised into two categories of adequate and inadequate. General health literacy was predicted by age, education, gender, income and functional health literacy. Functional health literacy was predicted by age, education, gender and income. Four independent variables were represented by dummy variables. Age was represented by three dummy variables; 36-65 years=age (1), 65 years and older=age (2) and 25-35 years was designated as the reference group. The other variable (education) was also represented in three dummy variables; Partial qualification=education (1), Qualification=education (2), and No-qualification=education was designated as a reference group. The other two variables gender and functional health literacy were represented in two dummy variables. They were females=gender (1) and males=gender was designated as a reference group; adequate functional health literacy= (1) and inadequate functional health literacy was designated as the reference category. Income was a continuous variable in this analysis.

The quality of life was another variable that was explored by using excel as recommended analysis by Bradley (1994). Two initial overview items to assess the quality of life was part of the SPSS analysis while rest of the analysis was carried out on excel to

determine the individual effects of diabetes on different domains of life along with weighted impact score and average weighted impact (AWI).

4.9 Study two: Exploring health literacy through Photovoice

4.9.1 What is Photovoice?

Photovoice (PV) is a qualitative research method that uses still pictures to document the participant's health and community realities (Thomas & Irwin, 2013) and then integrates photographs and critical reflection on these photographs to examine the issues according to the perspective of the community members (Wang, 2003). Initially, photovoice was developed by Wang with the help of Burris (Wang & Burris, 1994. 1997). Later it was expanded through collaborative efforts with other colleagues currently recognised as the photovoice methodology (Thomas & Irwin, 2013).

PV is based upon the assumptions that people are experts on their lives and they can capture their knowledge and their perspectives by using photography (Wang & Burris, 1994). PV has three main goals: 1) to record and reflect on the strengths and concerns of their community, 2) to promote dialogue and knowledge about personal and community issues through large and small group discussions of their photographs and 3) to reach policy makers (Wang, 1999). Participants use photographs to discuss their knowledge in a focus group or an interview, and many potential options can be used to exhibit the knowledge created by the participants (Wang & Burris, 1997).

The PV method provides participants, who traditionally have little voice in community policy decisions, with training in photography, critical dialogue, photo captioning and policy advocacy (Kramer, Schwartz, Cheadle & Rauzon, 2013). Overall PV is a tool for communication, using visual artefacts and a grass root approach to community

development and social action. PV is an effective mechanism for sharing the perspectives of those who may be marginalised or not often heard. According to Wang (2006), PV is a method that enables people to define for themselves and others what is worth remembering and what needs to be changed.

4.9.2   Theoretical underpinnings of Photovoice

There are three noteworthy perspectives that have a significant impact on the development of PV method: 1) empowerment education, 2) feminist theory and 3) documentary photography (Wang & Redwood-Jones, 2001). All three theoretical frameworks emphasise community participation for the purpose of a social action. The theoretical frameworks begin by directing change at the individual level, transforming perspective such as self-worth. The focus is then directed at the community level to improve the quality of life and then finally at the institution level to enforce change through policies (Wang & Burris, 1994).

First, empowerment education theory is based on the work of Paulo Freire, a Brazilian educator who used participatory strategies in adult literacy programs. Freire proposed an approach to learning that engaged teacher and learner as co-creators of knowledge. Wang and Burris (1994) used Freire's educational approach to design PV. Freier's drawing methods, photographs and stories were used to identify the significant community issues, have a critical reflection on the contributing factors, finally to look for the possible solutions for community empowerment (Wang & Burris, 1997).

Second, feminist theory informed the development of PV as it assumes that people have expert knowledge of their lives (Wang & Burris, 1994). PV values the knowledge put forth by the women as a vital source of expertise while addressing the needs of the assessment through such a powerful tool for visual images (Wang & Burris, 1997). It states

that anybody can learn to use a camera, and PV is particularly powerful not only for

women but also for workers, children, and people who do not read and write in the

dominant language or people with socially stigmatising health conditions. It also

recognises the expertise and knowledge that these people have about their lives and

communities that professionals and outside people may lack (Wang & Burris, 1997).

PV has roots in the documentary photography developed by Jo Spence a British

photographer and educator (Spence, 1995). According to this approach, cameras were

given to the individuals to document and discuss their experiences with the goal of

confronting stereotypical visual media (Spence, 1995). In the same way, PV give the

cameras in the hands of the individual to document their lives (Wang & Redwood-Jones,

2001) to bring change in their lives and communities and not merely passive subjects to

other people's intentions and images (Wang & Burris, 1997). Being a member of the

community has more experience to reflect on their lives than the experienced

photographers and journalists (Wang 1994).

4.9.3 Key concepts in Photovoice

Wang (1999) has discussed five key concepts based on previous projects that had applied

PV methodology. Firstly, ***Image teaching*** to provide a site for learning that may

profoundly influence people's health and well-being. Images contribute towards how we

see ourselves, how we define and relate to the world, and what we perceive as significant

or different. Secondly, ***Picture can influence policy*** by contributing to how individuals

look at themselves and images as well as the broader society of which they are a part of.

Thirdly, ***Engagement of community members*** with cameras and providing an opportunity

to the community members who ought to participate in creating and defining the images

that shape healthful public policy. Fourthly, ***exchanging ideas with relevant policy makers***

and stakeholders is one of the key concepts of PV, to influence policy by involving,

participants, policy makers, community members and other relevant stakeholders over the

images of their interest. Lastly, ***Enhanced individual and community action*** as PV has a

unique contribution in motivating individuals and communities towards taking actions.

These key concepts can distinguish PV projects from the other traditional research

methods. PV has a broader aim to influence the policy but the direction to shape the policy

comes from the grassroots level. Community engagement throughout the PV project

provides a unique opportunity to the participants to record and reflect on the community

issues according to their perspectives. It provides an opportunity to the communities and

individuals who might not otherwise have an opportunity to have a say in shaping or

influencing the policy making process. Highly engaged processes with the intended

community members can have more widening effects that can mobilise individuals

towards actions, in that way it has more profound community benefits than the traditional

research approaches. PV method is grounded in the understanding that policies derived

from the integration of local knowledge, skills, and resources within affected populations

will more effectively contribute to healthful public policy (Wang, 1999). PV is a flexible

method that has been employed with culturally diverse groups to explore the community

health issues and well-being needs (Wang & Burris, 1997). PV method is now a widely

used research strategy that enables researchers to facilitate groups/individuals to overcome

social barriers and communicate with other group members as well as with policy makers

(Thomas & Irwin, 2013).

Moreover, this powerful research methodology provides researchers with insight

into communities that would not be possible to have through other traditional research

methods. This method documents daily participant's struggles in more depth and a

contextually relevant manner. The process allows the voice of participants to be heard

through photos, stories, and individual and communal photo boards (Yankeelov, Faul, D'Ambrosio, Collins & Gordon, 2015). Minkler (2000) noted the importance of the participatory research strategies because the findings have local relevance and interpretation of these findings can have more validity within a particular context/setting. As well as being helpful in translating the findings into culturally appropriate policies and programs.

The application of PV methodology is appropriate when assessing the personal, social, economic, and environmental factors that influence health (Woda, Haglund, Belknap & Sebern, 2015). In reference to present research, there are many factors that affect the self-management of diabetes, particularly people belonging to ethnic minorities. Understanding one's level of consciousness may also assist in developing interventions appropriate to the person's perspective on self-management of diabetes. As discussed in Chapter 3 (South Asians, diabetes and health Literacy) there is research evidence available that suggests improving diabetes self-management through educational strategies and improved health literacy levels of the individuals. The development of interventions specific to South Asians living with diabetes thus signifies the need to understand their perspective in the management of diabetes. According to Goodley and Lawthom (2005) research with the communities can allow marginalised communities to think again about their own communities and themselves in the way that may promote self-emancipation over social exclusion (from this action could occur in a more coherent and meaningful fashion).

Estacio and Comings (2013) considered participatory research as one way to engage community members in understanding and developing competencies in health literacy. It has also been described in the literature review (Chapters 2 & 3) that health literacy has been associated with improved health outcomes and also considered important

in the management of diabetes. The next section will describe the use of PV as a method in this research project and explored the factors and issues that are important to health literacy needs as per perspective of South Asians living with diabetes in the UK.

4.9.4 Photovoice method

PV explores the following aims:

- The management of diabetes in the daily life of South Asians in the UK.

- How participants are using health care information/services in the management of diabetes and what things should be considered according to their specific needs as a South Asian ethnic community.

- To examine the management of diabetes and their cultural needs within health literacy context.

4.9.5 Participants

11 participants were recruited. This sample size is characteristic of research projects employing participatory photography (Kindon, Pian & Kesby, 2007). Purposive sampling was used to recruit the participants. All participants are living in the Stoke-on-Trent area, are diagnosed with diabetes and have a South Asian ethnicity. South Asian groups do have heterogeneity based on the country of origin, religion, and socioeconomic status. The present research aims to explore the concerns and issues of people belonging to Pakistani origin. Three females and eight males completed the PV workshops. Participants were made anonymous. All the names provided are pseudonyms. Participants demographic information described in Table 4.3 (p. 157).

Table 4.3: Participant's demographics

Names	Age	Gender	Education	How long living in the UK	How long living with diabetes	Other health problems	Doing exercise?
Tayab	43	male	LLB	8 years	5 years	Cardio, backache	no
Ibrar	59	male	College	10 years	2 ½ years	No	yes
Saleem	69	male	No	45 years	15 years	Hypertension, cardio	no
Zafar	39	male	Masters	25 years	6 years	No	no
Nasib	55	male	No	15 years	7 years	Hypertension, cardio, obesity, foot problems	no
Abid	45	male	Diploma	5 years	3 years	Hypertension	yes
Saeed	48	male	Masters	6 years	5 years	No	no
Umer	42	male	LLM	12 years	4 years	Psychological, Foot problems	no
Fatima	38	female	High School	16 years	7 years	Asthma, psychological problems	no
Wajeeha	39	female	Masters	12 years	1 1/2 years	No	no
Parveen	52	female	Masters	10 years	2 years	No	no

4.9.6   Materials

Information sheets were handed to those who showed interest in the project. The individual participant folder contained: the information sheet (Appendix N), a form of consent to taking part in the project, a form of consent to use photographs in the analysis and

exhibition (Appendix O), a form for others to consent to being photographed (Appendix P), a topic guide (Appendix Q), and an information sheet about participant safety and ethics (Appendix R).

4.9.7   Procedure

PV ran in four stages.

4.9.7.1   Stage 1: Recruitment

For this project, 11 participants were recruited for PV. Participants who completed the survey research (Phase I) were asked to participate in PV. Following consent, further steps were taken to carry out the PV method. During the recruitment process participants were given a clear explanation about the purpose of the project and what might be the expected outcome of their participation in this research. Recruitment was an exhausting process because participants were reluctant to take part in PV due to its long-term commitment to the whole research process. After all the efforts utilised for recruitment, 20 people agreed to be part of the study, but after the PV workshop finally there were 11 participants who completed the PV project. Participants who did not turn up after the first workshop they did not give any reason for not taking part in this project.

4.9.7.2   Stage 2: Photovoice workshops

At this stage after establishing the PV pool, workshops were conducted with the participants. Four PV workshops were conducted (two to five participants in each workshop) according to the individualised preferences of the participants (i.e. female participants were included in the workshop with male participant to whom she feel comfortable) in their native language (Urdu, Punjabi). This was done to ensure the cultural

norms and traditions of this ethnic community. It was also helpful to increase the engagement such as free expression of concerns and issues (particularly female participants) as a participant of PV project.

All the participants preferred to use their mobile cameras to capture the photos, and they were happy how to use their phones so no training was needed in this context. However, participants were encouraged to take the pictures that were be clear, and it was also reassured that this is not about their assessment of taking pictures, so feel free to take pictures that are appropriate for them. Although producing professional images is not the purpose of a PV project, creating images that are interesting and compelling will invite more viewers to explore participant's completed projects and narratives (Becker, Reiser, Lambert & Covello, 2014).

The ethical issues were discussed with the participants. All the participants consented before taking part and were advised they could withdraw at any time during the research process if they wished. It was also discussed with the participants that they should not take a picture of any person identifiable in the picture without seeking permission from them. Wang and Redwood-Jones (2001) discussed the ethical issues pertinent to an image taken in a PV project such as intrusion into the private space of a person, the disclosure of embarrassing facts about the individuals, being placed in a false light by the image and protection against the use of a person's likeness for commercial benefit. Further, ethical issues that participant need to consider before taking photos include: obtaining consent before taking photos of a person, and developing guidelines and discussing it with the participants related to taking photos in private and public spaces. The written protocol was provided along with discussion in their native languages to ensure the understanding and comprehension of the PV project.

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To make sure the PV methodological approach of creating balance and shifting the power towards participants in designing the research aims and issues as part of PV project, participants were encouraged to take part in designing the specific areas to explore in PV. It was discussed and agreed with the participants to reflect their experiences of diabetes management in their daily life, access and utility of healthcare services in diabetes management and their health literacy needs in all of this process.

4.9.7.3 Stage 3: Taking the pictures

In this stage, participants were actively involved in taking photos. There were options given to the participants' whether they use a disposable camera (provided by the researcher) or use their cameras if preffered. All of the participants agreed to use their mobile cameras for taking photographs. They were given two weeks to complete this stage. The researcher was in contact (through mobile texts and calls) with the participants to ensure the process was on track or to ask if they are struggling with anything. The photographs were printed out as the participants finished taking photos. Printed photos were sent back to the participants in a sealed envelope to ensure confidentiality. Participants were given the option to decide which photos they want to share with the group and which ones they don't. After getting their consent extra copies of the photographs were printed out to include in the groups discussions and analysis.

4.9.7.4 Stage 4: Photovoice group discussions

After arranging the chosen photographs, participants were invited to have group discussions on the pictures. The participants were free to speak the language they preferred to use in the discussions. All the participants used their native language (Punjabi). In this session, participants were asked to talk about the pictures and describe them in detail.

SHOWeD card (see Figure 4.5) was used as a starting point to have a reflection on the photographs taken.

Figure 4.5: SHOWeD card

S	What do you **See** here?
H	What's really **Happening** here?
O	How does this relate to **Our** lives??
W	
e	**Why** does this situation **exist**?
D	What can we **Do** about it?

Then they were asked to arrange the pictures into groups and categorise them into themes. After obtaining the consent, participants' discussions were tape recorded and later transcribed and analysed. Four group discussions were arranged that include two to five participants in each session (as in PV workshops). Group discussions were arranged according to the needs and preferences of the participants, to ensure the cultural safety lens and compatibility with cultural expectations (Fang, Sixsmith, Lawthom, Mountain & Shahrin, 2015). Female participants were interviewed with the male participants who have a previous introduction or any relation with the participant, while male participants did not have any such kind of preferences.

The role of researcher's background; (as discusses at the start of this thesis (p. xvi) and in the reflexivity section (p. 169) belonging to the same ethnic community, speaking the same language and having shared cultural descent all play a significant role throughout

this research project to make it a success. As discussed earlier PV methods can be appropriate research approach with the people who are not a native speaker of the dominant language and living as an ethnic community. The researcher's use of the native language of the participants encouraged them to express their thoughts in a more comfortable and confident manner. This advantage of language and same ethnic status not only helped in the recruitment process but especially during the focus group discussions it was a very powerful element to have more conducive sharing of ideas from the participants. Next section demonstrated how the researcher made an interpretation of the research data collected in PV project.

4.9.8   Data analysis

Thematic Analysis (TA) was used to explore in detail the daily life experiences of participants with diabetes. TA is a method for identifying, analysing, and reporting patterns (themes) within data (Braun & Clark, 2006). A theme can be defined as something important about the data related to the research question and represents a level of patterned responses or meaning within the data set (reference). Themes can be identified in one of the two primary ways in the thematic analysis: in an inductive or 'bottom up way' or deductive or 'top-down way'. An inductive approach means that themes identified are strongly linked to the data themselves (Patton, 2001). The inductive analysis is, therefore, a process of coding the data without trying to fit it into a pre-existing coding frame, or the researcher's analytical perceptions. In this project, as the main aim was to explore how the participants are managing their diabetes and what are the factors and issues that are important about health literacy by considering their cultural perspective. To achieve this aim, the inductive approach was utilised.

TA minimally organises and describes the data set in detail; however, frequently it goes further than this and interprets various aspects of the research topic (Boyatzis, 1998). TA is different from other approaches such as grounded theory or discourse analysis in the way that it does not rely on pre-existing theoretical frameworks that make it suitable to explore the under-researched area and particularly relevant to the health services studies (Gellatly, 2011).

As mentioned earlier that four focus group discussions were conducted according to the preferences of the participants in the PV research process. In each group discussion photographs were arranged according to the themes identified by the participants. This shared initial analysis was strengthened with the analysis done by the researcher. TA was achieved manually without the use of any qualitative data analysis software. As the data was collected in the native language of the participants, the researcher conducted the analysis in the native language of the participants; later the quotes of the participants narratives were translated into the English. In conducting thematic analysis, the procedure and stages described by Braun and Clarke (2006) were followed. First, several readings of each transcript were conducted to achieve familiarity with the data. Data was collected in the form of pictures taken by the participants that followed by their reflection through SHOWeD card that further lead to having group discussion between the focus group participants. The researcher conducted the focus group discussions (n=4) with the participants that were the first step to becoming familiar with the data, and it provided initial thoughts and built interest in the data. At the first point, audio-recorded data was transcribed by the researcher by play script method that further enhanced an in-depth familiarisation with the data. Transcripts were read again and again to become more familiar with the data. Once the whole of the transcribed focus group discussions was read out to develop an insight into an overall trend and thoughts present in the data. Although

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reading and re-reading were a time-consuming process, it gave in-depth familiarisation with the data. Key points and extracts were highlighted, to indicate potential patterns. During this reading phase notes were taken for anything interesting that emerged during reading through the data. Initial notes were made on the transcripts to identify segments of data which appeared to be important or significant, as defined by the researcher, diabetes management in daily life, use of health care services within health literacy context. Table 4.4 (p. 164) provides an example of notes applied to a short segment of data. Appendix S illustrates a table charting all the notes made across four transcripts.

Table 4.4: Data extract, with initial notes applied

Data Extract	Initial Notes
Most of our people think that they will have diabetes as they are taking too much sweet.	Conception about cause of diabetes
They do not know anything about their diet. They do not care about their meal timings.	Do not care about eating timings
Eat on proper time and what you are eating is very important. (Saleem, p.85, 2507-2511).	Knowledge about healthy eating pattern

The second stage involved a process of data reduction and organising the data into meaningful groups (Braun & Clark, 2006). Therefore, the initial note that fitted under a specific category was identified and placed under an initial code. There was no intentional effort made to delete any initial code at this stage and to make sure that any loss of data could be minimised. A description of what the code meant and a source of the code was noted. Table 4.5 illustrates an example of how notes were classified into codes.

Table 4.5: How notes were classified into codes

Initial notes/patterns	Lines (Names)	Initial codes
Conception about cause of diabetes	2507-2511(Saleem)	South Asian traditional diet as risk
Popularity of sweets	227-236 (Naseeb)	
Deep fried food	194-1978(Parveen)	
Female role in cooking	1140-1149(Wajeeha)	
Food as social status	576-587(Fatima)	
Peer pressure on social gatherings	3559-3567(Umer)	Cultural norms and traditions
Do not care about eating timings	1999-2006(Ibrar)	
	4032-4041(Tayyab)	
	1332-1347(Saeed)	
Eating in large portions	2873-2888(Zafar)	Eating habits and behaviours
Knowledge about healthy pattern		

The next step was to analyse all the codes, which involved searching for connections, and considered how the different codes combined to form over-arching sub-themes. The focus was on identifying broader patterns in the data and emerging sub-themes, which identify what the data meant. The sub-themes were identified by bringing together components of fragments of ideas or experiences and pieced together to form a comprehensive picture of participants' collective experience (proposed sub-themes). Table 4.6 (p. 166) illustrate an example of how this has been achieved. Key phrases from the participants' transcripts that supported the sub-themes along with photos were also identified at this stage. Appendix S provides a full table of all sub-themes produced from the analysis.

Table 4.6: How codes were combined to form sub-themes

Initial codes	Sub-themes
South Asian traditional diet as risk Cultural norms and traditions Eating habits and behaviours Food as treating element for diabetes	Lifestyle
Knowledge and actions Cultural norms and traditions Perceived barrier to physical activity	
Medicine intake and adherence Alternative cultural medications	Clinical measures of diabetes care
Perception and actions about blood glucose monitoring External support	
Limited utility of written material Personal and family resources Civic health literacy	Personal skills and capacities

The final stage involved a process whereby sub-themes were examined amongst each other and combined to form main themes. This was the stage of the analysis where the relationship between code, between sub-themes and the main overall themes, were examined. A provisional heading was created for each emerging main theme. Table 4.7 (p. 167) illustrate an example of a final theme with the sub-theme included in that theme. At stage four of the thematic analysis, the refinement of the candidate themes was done. The decision was made about the validity of themes whether it could be a theme or it should be deleted due to lack of data support. After this, a thematic map was developed to describe the final themes. Again data were read and re-read to check that themes are working well with the data set and secondly to find out anything new that was missing in the previous

analysis. As in qualitative analysis, there are no rigid ways of doing analysis, and it is common to go back and forth to make sure validity of the data analysis. At the end of this stage, there was a clear idea of what different themes are and overall story of the data in the research project.

Table 4.7: An example of final themes and sub-themes within

Provisional named theme	Final theme	Sub-theme
Individual-context	Illustration of diabetes management in day-to-day	Lifestyle
		Clinical measures of care
		Personal skills and capacities

Once the procedure had been carried out for the first transcript, the same procedure was carried out for the others. Each transcript was analysed as new. Similar themes across different transcripts were identified, as well as those that were different and exclusive to a particular participant. As photographs were the important part of data in PV, first effort was made during focus group discussion to categorise the photographs according to the positional theme categories with the participants.

A define and refine process was done by ensuring coherency of the themes that supported by the participant's narratives and photographs. It was also mentioned that why this theme was interesting and important to mention. Overarching themes and the sub-themes were defined. There were titles/names given to the main themes and all the sub-themes within the data set that explored health literacy through PV (see Appendix S). Further to the issues of trust, validity and trustworthiness in the PV discussed in the following section.

4.9.9   Validity, reliability and trustworthiness

Trustworthiness of the research is of paramount importance when designing a study; traditional researchers use validity, reliability and objectivity as a measure and criterion of the trustworthiness of the research process (Sarantakos, 2013). In qualitative research, trustworthiness is used to determine whether findings of the study are reliable. In this study, the researcher collected data through participants' photographs, critical reflection on the photographs, journaling, and focus group discussions with the participants. The researcher also used various levels and phases of coding the data and defining themes. Supervisors also reviewed the data analysis process thoroughly to ensure the quality and validity of the interpretation presented. A clear record of the audit of the data was preserved throughout the analysis. It was assured that identified themes referred to the participant's narratives and supported by the participant's accounts and photographs. Further details about the position of researcher throughout the research process discussed in the reflexivity section (p. 169).

This study holds ecological validity as data was collected from the participants in their natural setting. This study does hold internal validity, "internal validity is the term used to refer to the extent to which research findings are a true reflection or representation of reality rather being the effects of extraneous variables" (Brink, 1993, P.35). The present study used PV method that characterised by the engagement of participants throughout the research process from defining the issues to explore, deciding what to capture for photographs, a reflection of photographs and discussion of the photographs. All these steps do reflect the true representation of the participant's reality about their daily lives.

This study has also used member checking for enhancing the reliability and validity of the data collected, that shifting the validity procedure from the researcher to the

participants. Lincoln and Guba (1985) described member checks as "the crucial technique for establishing credibility" (p. 314). In this process, the PV data and interpretations were sent back to a sample (n=4) of participants (who can read English and agreed to do so) so that they can confirm the credibility of the information and narrative accounts. In this way, participants added credibility to the qualitative study by having a chance to react to both the data and the final narrative. As the qualitative paradigm assumes that reality is socially constructed and it is what participants perceive it to be. Involving participants in assessing whether the interpretations accurately represented them can enhance the credibility of the qualitative research (Creswell & Miller, 2000). Further, the reflexive position of researcher in the PV research process is discussed in the following section.

4.10 Reflexivity

Reflexivity involves the researchers active recognition of the dynamic nature of research where one situate his/her roles, values, assumptions and social position within the context of the research and how these interact to influence the research process and its outcomes (Smith, 2008). According to DeSouza, "Reflexivity can be used in varying context and with different aims, to enhance the credibility and rigour of the research process, as well as make transparent the positionality of the research" (DeSouza, 2004, p.474). Reflexivity is complex and multi-faced and may be considered, and described, in a number of different perspectives. Chamberlain (2004) has described five general types of reflexivity listed in Box 4.1 (p. 170).

Box 4.1: Types of reflexivity in research (Chamberlain, 2004, p. 126)

Reflection- Self-reflective activity or reflexive introspection about the processes of research that does not impact on the research activity or appear in the published accounts of the research.

Methodological reflexivity- Reflection about the methods and practices of the research, involving active consideration of the roles and values of the researcher in shaping the practices of the research, and of the relation between the researcher and the researched.

Epistemological reflexivity- Reflection about the epistemological and ontological assumptions underlying the research, and how these shape the research practices and interpretations.

Meta-theoretical reflexivity – stepping back from the research activity and considering it place an role as social activity; disengagement from the research for the purpose of critically examining the activity; deconstruction of the research and/or the researcher's role to determine taken for granted assumptions; using deliberate variation and disruption of the activity and undertaking an examination of the consequences arising.

Textual or hermeneutic reflexivity- Consideration of the meanings and possible alternative interpretations offered in texts about the research.

Willig (2008) has described two types of reflexivity; personal reflexivity that reflects the researcher's own stance, social identity and background; and epistemological reflexivity, related to the effects of methods on outcomes and conversely how carrying out the research lead to a change in these. Personal reflexivity is considered more important in qualitative research while epistemological reflexivity is expected to be part of both quantitative and qualitative research. Shaw (2010) has discussed why this is a particular case for qualitative research because mainly data gathering involves engaging with other people's language, the stories they tell, and their experiences. She further explains that our job being a researcher is to make sense of these stories and experiences in a meaningful way with a view of learning more about humankind and often to affect change that may be regarding influencing policy, practice or enhancing understanding at an individual or institutional level.

In this project, I have applied mixed methods research approaches to study the phenomena under study. Although personal reflexivity is more important in qualitative

research while it can also be extended to the quantitative research process. Walker, Read and Priest (2013) have used reflexivity in mixed methods study. The initial part of their study was quantitative, collecting baseline data for further phases of the research. Walker, Read and Priest thus suggest a lack of reflexivity in quantitative research, and they provide two reasons for not doing so. The first reflexivity was not seen to add anything to the data collected through quantitative research that is considered 'factual' and secondly, it may have given the impression of inadequate controls that can undermine the quantitative research's validity. Although it was concluded that to have reflexivity during quantitative phase can have benefits to improve and inform future research practices. It can reduce biases and add transparency in the research process and more useful to provide a broader view of the research process.

Transparency is central in producing a trustworthy empirical report (Lincoln & Guba, 1985), and providing a rationale in writing reflexively to indicate the motivations for discussion in research design and inserting discussions of context from both perspectives of the researcher and those researched. This will help to elucidate the research process and indicate that a reflexive approach has been adopted (Shaw, 2010). Smith (2008) suggests reflexivity is an important part of transparency within a study and can be used as a method of reducing the researcher's influence on the study. However, Holloway and Jefferson (2007) argue that the researcher's own subjectivity can benefit the analysis process. Reflexivity during the analytical process can serve as a guard against good and bad interpretation. They have defined good as being honest and having an open interpretation of the data, and bad, where there is manipulation of the interpretation of the data to ensure that data reveals what the researcher is looking for.

It is important to remember that data is interpreted through the eyes of both the researcher and the participants, and there is an impossibility of eliminating subjectivity in

this process. Being reflexive means that the researcher is acknowledging this and allows the reader to interpret the findings according to their own perspective (Cluett & Bluff, 2006). According to Reed (1995), the biggest issue that a researcher faces is the way in which their knowledge and identity affect the collection of data. A pragmatic approach to deal with this dilemma is in using a reflexive process. This is required to prevent prior knowledge distorting the researcher's perception of data. For that, it is import to have a clear agenda before the start of the research. Making personal and intellectual biases plain at the start of the research process is important. This can enhance the credibility of the research process (Pope & Mays, 1999). However, Jomeen (2006) argued that reflexivity not be to provide the confessional of a researcher's experience, but it is there to demonstrate a methodological and theoretical appreciation, openness and a truly honest awareness of the researchers and the participants.

Reflexivity is referred to the researcher's self-criticality about the influence of their subjectivity in the research process and outcomes. Instead of eliminating subjectivity in the research process, it is emphasised to have a critical reflection on one's self as a research instrument (Guba & Lincoln, 2008). In my view, critical reflection should be built within the ethics and pragmatic nature of the research, in the field of health psychology that can have an important implication for policy and practice to make a significant contribution to the lives of the people. This is particularly important in this research, as belonging to the South Asian community researcher's subjective experiences can have an influence on the research process and findings. Keeping a clear frame of neutralising personal biases in this research was considered an essential element. A range of approaches to reflexivity have been presented here; however, in this thesis, Willig's approach of personal and epistemological reflexivity will be used as a way to cater reflexive process of qualitative and quantitative approaches along with addressing any issues of transparency. The

personal reflections were discussed at the start of the thesis (p. xvi) that how the researcher's individualistic traits, culture and academic training contribute to shaping this thesis and research process. In this section, the focus is to address the epistemological reflexivity during this research project.

4.10.1 Epistemological reflexivity

Although I have tried to minimise the effects of my subjectivity and personal biases in some ways it has helped me throughout the research process. Living in the UK as a member of the ethnic group, with shared cultural traditions and norms, helped me to understand the research that has the main focus on understanding the cultural perspective in diabetes management: exploring health literacy needs of the South Asian community in the UK.

Though I have acknowledged the existence of multiple realities and presented an argument in favour of combining multiple methods of inquiry that should be based on an achieve of the research agenda. I have the stance that individuals share their experiences and construct their subjective reality influenced by different aspects of society (i.e. material resources, culture, beliefs, ideologies and other mode of the power structure in the society). People construct their reality through critical reflection on their surroundings and living conditions, hence construct of reality with the participants is key to the research process. This approach towards research leads to my methodological choice of inquiry for the qualitative part of this thesis, participatory research based on the Freire's (1970) approach towards constructing reality through a dialogue process.

I think conducting the research with marginalised communities such as ethnic groups needs to have more collaborative and participatory approaches, by which I mean to bring people together in a more incolusive way to share their experiences and to have an

opportunity to discuss with the researcher together to address the issues that are important to them according to their own perspective. This collaboration and interaction with participants throughout the research process allow the researcher to become more reflexive. This also deals with the conventional power relations during the research process as in participatory research and in this case an opportunity (PV) was given to the participants to have more power and control in the research process. In the participatory methods, power delegates to the participants and it is fair to say that in some cases it can revert the power from researcher to the participants. It has been earlier mentioned that interpretation is the process where subjectivity of the researchers can have influence, however, that has been tackled through sending back the qualitative analysis to the participants to have validity approved according to their perspectives.

Although reflexivity is considered more important for qualitative research, however, Walker et al. (2013) also mentioned the significance of reflectivity during quantitative research could be a valid means to make research decisions. In the process of data collection this help to reframe the data collection procedure, as in few initial face-to-face interviews when the participants were asked about the demographic information at the start particularly the income they feel reluctant that it is for the research purpose why you are asking about income. This was resolved through the application of all the other measures first, and at the end, participants were asked for information about the demographics, and it went well with rest of the data collection without any concern raised by the participants. Despite these considerations, majority of the participants did not respond to the question related to their income.

In the data collection process, it is believed that participants will share their views on what they feel are safe and acceptable (Cluett & Bluff, 2006). In this project the use of participatory research 'PV' thus enables the participants to feel free and comfortable to

share their experiences and opinions without any fear and reprisal. By using PV data alongside the survey research in this study, we can enhance the reliability of the data and increase the probability that new programs accurately reflect needs of South Asians living with diabetes. I am using this project to understand the health inequalities and how diabetes management can be improved and health literacy can be enhanced in South Asians living in the UK.

In the case of qualitative research, I struggled to recruit participants due to the participatory nature of the research. Participants were reluctant to be part of the PV due to prolonged engagement process. To increase the recruitemnt of the participants I contacted the people who were already known to me that help to motivate them to be part of this project.

I described some of the themes to take pictures for PV project but made an intentional decision not to discuss too much about themes before participants went out to take photos. As a pedagogical choice, I wanted participants to engage in a constructivist experience where they create their own knowledge.

Engaging in a new methodology (PV) was a risk for me as a researcher. I am making myself vulnerable and counting on a lot of trust. If there is not adequate time and facilitation, participants could simply leave the project with more concrete prejudice and misinformation particularly with South Asians community where I was already struggling to recruit the participants for this research. I have to be clear that what I am going to discuss about diabetes management and what I can offer them that they will not have misguided information provided.

It is a continued struggle for my desire to hold on to the participatory nature of PV. Belonging to a South Asians community as a researcher ensured that I and the participants

had a common knowledge base and will be able to learn more strategies for diabetes management. Thus highlighting the needs to improve health literacy levels in this community.

PV has proven to be a method for engaging groups who have difficulty articulating their view in traditional research (e.g. second language), thus increase the scope of potential participants. In this project, I struggled with engaging participants, but on the other hand, participants who were willing to participate were more actively involved in this project.

During the focus group discussions with the participants, an intentional effort was made to have focus group discussions arranged according to the preferences of the participants. Female participants have a discussion with the males with whom they feel comfortable. That allows more detailed responses from the female participants. Male participants were invited for group discussion altogether. Although these also raised other concerns over convenient times and dates that were suitable to all participants. After keeping a contact and continued the effort to arrange times which best suited the final arrangements were made to have focus group discussion.

The focus group discussions were conducted with participants ranged two to five participants in each group, and it was realised that more participants in focus groups could have more effective in engaging participants, in a dialogue process and to elicit discussion among the participants. However being female known to a majority of the participants among males in conducting focus group discussions was a restricting element to the participants for free expression of the areas of their personal lives having been affected by diabetes. As one participant wanted to talk about the sexual dysfunction after diabetes, but

he did not explicitly say this by stating it, as we cannot say everything in front of females due to religious and cultural restrictions.

Finally and most importantly, in both studies in cases of face to face data collection during survey research and focus group discussions with the participant's language was a major factor. The researcher had used the preferred language of the participants thus enable the participants to express fully their experiences and what they want to say. One participant before the focus group discussion wanted to ask whether to speak in English or their our own language. So the word of ***our own language*** was very powerful to build rapport and gain the confidence of the participants to increase their participation in the focus group discussions.

5 Study One: Health Literacy Survey

5.1 Introduction

The aim of the survey was to assess health literacy levels among participants belonging to South Asians community in the UK. In this chapter the information will be presented about demographics (gender, age, ethnicity, household living situation, education, income, employment) and consider relationships between these variables. Health status, health behaviours (diet, lifestyle, smoking, alcohol consumption and exercise) along with social capital will also be explored. Health literacy level can also be determined by demographic characteristics; this chapter will also explore the association between health literacy and demographic variables (gender, age, education, and ethnicity) followed by the correlation analysis to examine the relationship between variables and logistic regression to predict the health literacy of the participants. In the last section results about the quality of life of the participants with diabetes are presented.

5.2 Descriptive analysis of the demographics

5.2.1 Gender

In total 350 individuals were recruited, 189 (54%) were male, and 161 (46%) were female.

5.2.2 Age

The age profile of the participants ranged from 18 to 78 years of age, with *M=34.82* and *(S.D=12.98).* The frequencies for the age are shown in Table 5.1 (p.179).

Table 5.1

Age profile of the participants (N=350)

Age	Frequency	Valid percent
25 or Younger	58	16.6
26-35	69	19.7
36-45	75	21.4
46-55	64	18.3
56-65	57	16.3
66-75	21	6
76 or Older	6	1.7
Total	350	100

5.2.3   Ethnic identity

Figure 5.1 presents the breakdown of the ethnic identity of the population sample. In relation to the respondents' ethnic identity 200 (57.14%) of the respondents indicated that they were Pakistani. 108 (30.86%) indicated themselves Indian, and 42 (12%) respondents recorded themselves as Bangladeshi.

Figure 5.1

South Asian ethnicity (N=350)
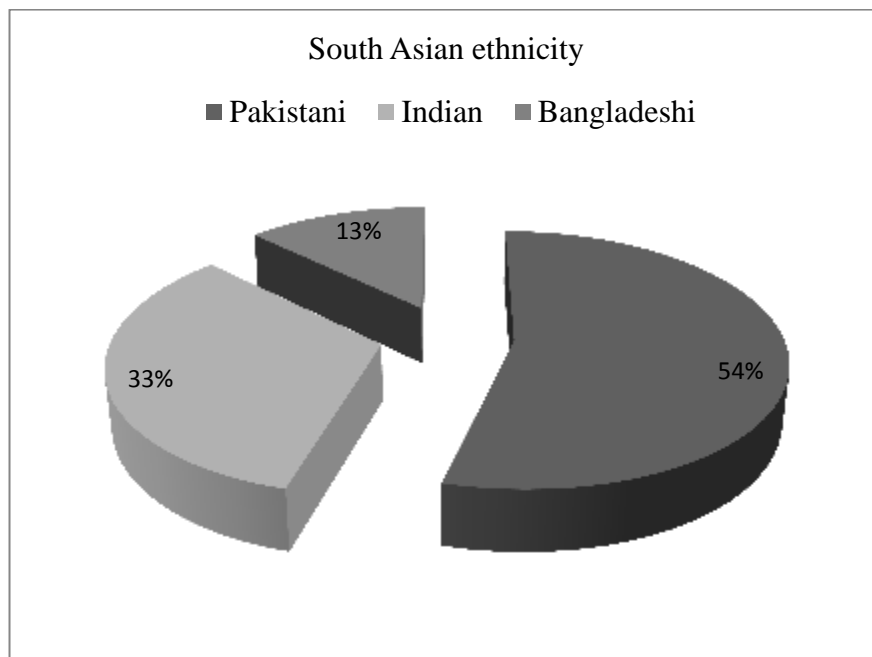
5.2.4   Household living situation

In relation to the household living situation, 87 (24.9%) of respondents stated that they own their accommodation outright, 161 (46%) indicated that they were living in accommodation owned with a mortgage or loan, whereas 27 (7.7%) live rent free. 11 (3.1%) of the respondents living in shared accommodation, 64 (18.3%) were living in rented accommodation (With or without benefits). The frequencies for type of accommodation are shown in Table 5.2.

Table 5.2

Type of accommodation (N=350)

Accommodation	Frequency	Valid percent
Owns outright	87	24.9%
Own with a mortgage or loan	161	46%
Lives rent free	27	7.7%
Shared accommodation	11	3.1%
Rents (with or without benefits)	64	18.3%
Total	350	100%

5.2.5   Educational attainment

Figure 5.2 described the level of educational attainment of respondents. 125 (35.7%) have

no qualification, 75 (21.4%) have education level below compulsory, 37 (10.6%) have

education till GCSE, 18 (5.1%) have A-level, 71 (20.3%) have degree level education, and

26 (7.4%) have foreign educational qualification.

Figure 5.2

Educational attainment (N=350)
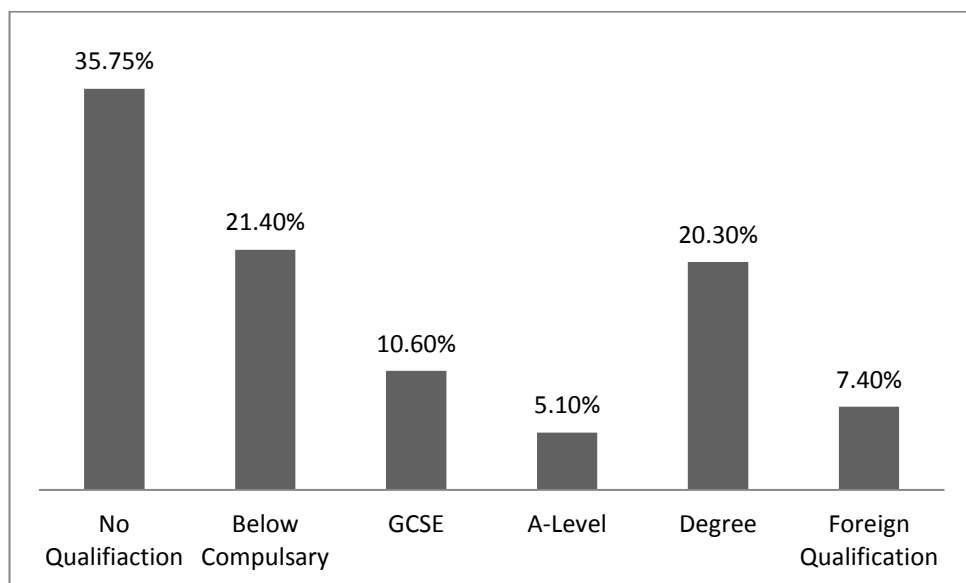
5.2.6 Household income

In relation to household income, the majority of the participants 44.6% recorded their response that they do not know or want to share information about their income, 9.1% had a weekly income in the range of £0-96, 12 % had income in between £97-192, 21.1% had income in the range of £193-385, 6.6% had income in the range of £386-479, 3.4% had income in the range of 480-575, and 1.1% indicated their income range in 576-672 and 2% recorded their income 673 and more (See Figure 5.3).

Figure 5.3

Weekly income (N=350)
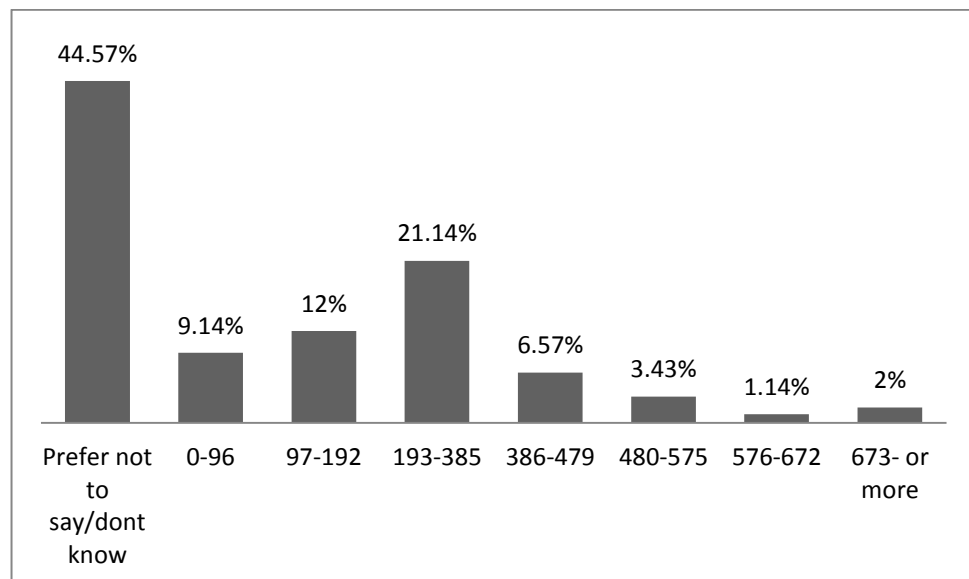
5.2.7   Working hours in a week

In relation to working hours in a week, 36.6 % recorded that they never worked, 10.6 %

worked less than 15 hours, 18 % worked16-30 hours in a week, 19.4 % recorded their

working hours 31-48 hours, 15.4 % were working 49 or more hours weekly. The

frequencies for working hours in a week are shown in Table 5.3.

Table 5.3

Working hours in a week (N=350)

Working hours	Frequency	Valid percent
Never worked	128	36.6%
15 hours or less	37	10.6%
16-30 hours	63	18%
31-48 hours	68	19.4%
49 or more	54	15.4%
Total	350	100%

5.3   Health status, health-related behaviours and social capital

5.3.1   Self-rated health

In relation to personal health 2.6% of respondents rated their personal health as 'very bad', 16.6% rated their health as bad, and 35.4 % recorded their health fair. 31.1 % considered their health as good, 14.3 % recorded their response as very good health. The frequencies for self-rated health are shown in Table 5.4.

Table 5.4

Self-rated health (N=350)

Health	Frequency	Valid percent
Very bad	9	2.6%
Bad	58	16.6%
Fair	124	35.4%
Good	109	31.1%
Very good	50	14.3%
Total	350	100%

5.3.2   Self-reported diet

With regards to self-reported diet, 56% of respondents reported they had a healthy diet, 15.7% said they do not have a healthy diet, 8% recorded they do not know what a healthy diet is and 20.3% indicated they do not know whether they have a healthy diet. The frequencies for self-reported diet are shown in Table 5.5.

Table 5.5

Self-reported diet (N=350)

Diet	Frequency	Valid percent
Don't know if I have a healthy diet	71	20.3%
Don't know what a healthy diet is	28	8%
No	55	15.7%
Yes	196	56%
Total	350	100%

5.3.3 Self-reported lifestyle

Of the respondents, 2.3% indicated that they had a very unhealthy lifestyle and 9.7% had a fairly unhealthy lifestyle. 39.4% respondents recorded their response as neither healthy, nor an unhealthy lifestyle and 39.4% indicated fairly a healthy lifestyle while 9.1% respondents recorded very healthy lifestyle. The frequencies for self-reported lifestyle are shown in Table 5.6.

Table 5.6

Self-reported lifestyle (N=350)

Lifestyle	Frequency	Valid percent
Very unhealthy lifestyle	8	2.3%
Fairly unhealthy lifestyle	34	9.7%
Neither a healthy nor an unhealthy lifestyle	138	39.4%
Fairly healthy lifestyle	138	39.4%
Very healthy lifestyle	32	9.1%
Total	350	100%

5.3.4   Smoking

With regards to smoking (see Figure 5.4), 72% of respondents had never smoked, 6% had

tried cigarettes just once or twice, and 22% recorded their response as they are used to

smoke.

Figure 5.4

Smoking behaviour (N=350)
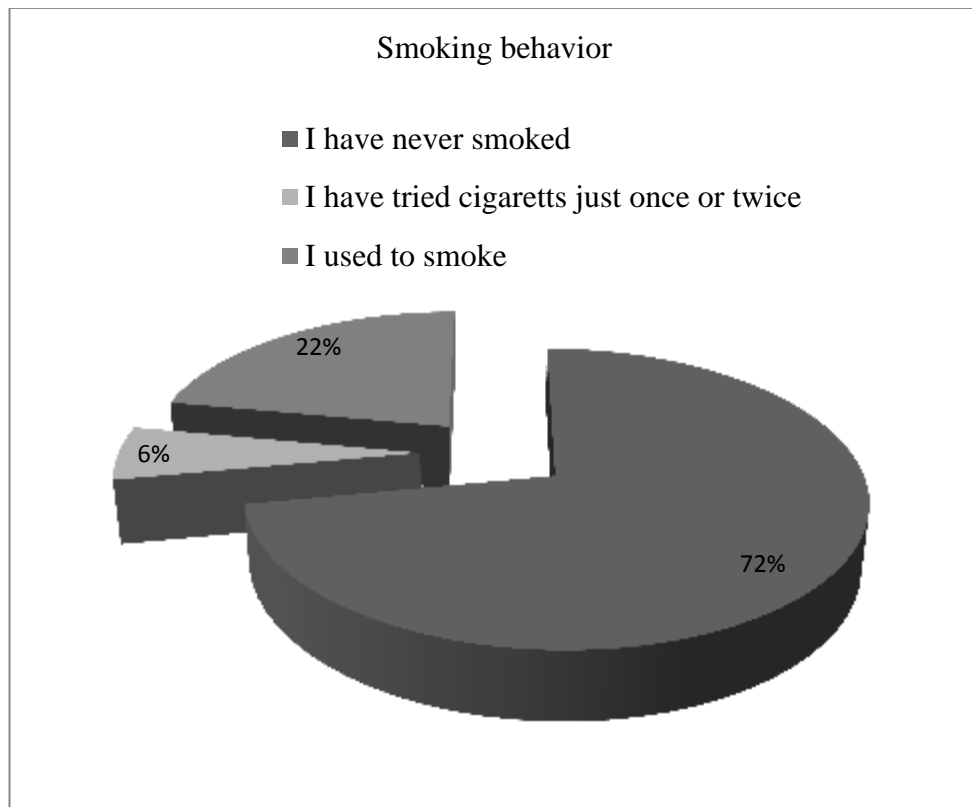
5.3.5 Alcohol consumption

In relation to alcohol consumption (see Figure 5.5), the majority of the participants 88.86% never consumed alcohol, 3.71% had less than once a month, 2.57% had 1-3 days in a month, and 4.57% 1-3 days a week and 0.29 % had alcohol every day.

Figure 5.5

Alcohol consumption (N=350)
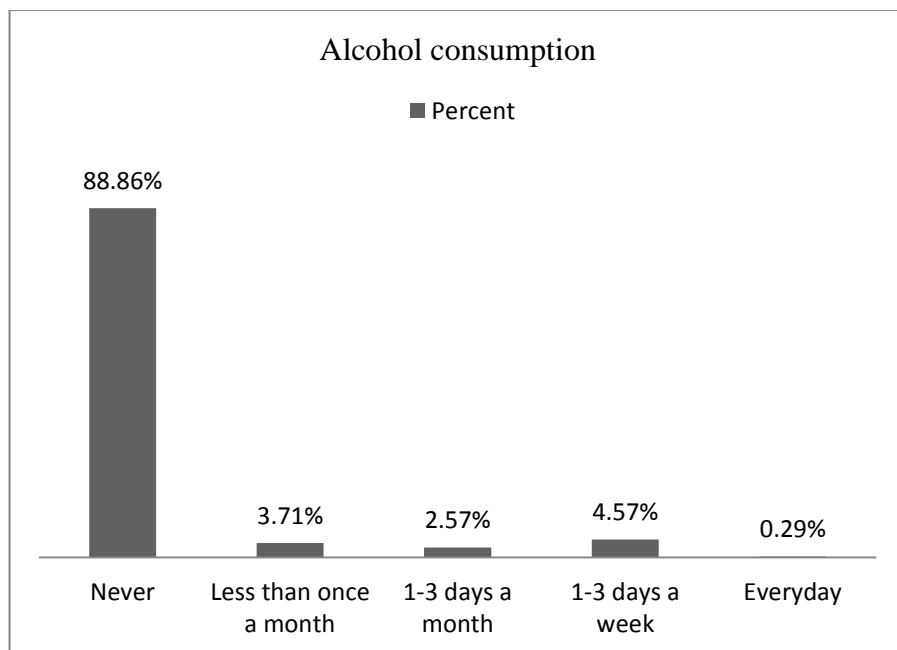
5.3.6 Exercise

In relation to exercise the majority of the participants, 49.1 % were not doing any exercise, 27.7 % exercised 1-3 days in a week, and 23.1 % exercised four days and above in a week. The frequencies for exercise in a week are shown in Table 5.7.

Table 5.7

Exercise in a week (N=350)

Exercise	Frequency	Valid percent
No exercise	172	49.2%
1-3 days in a week	97	27.7%
4 days and over in a week	81	23.1%
Total	350	100%

5.3.7 Social capital

Of the respondents, 86.57% indicated that they had a family member and friend available to talk and share their thoughts. 10 % had friends or family members while 3.43 % participants recorded they do not have any friend or family member to talk. The distribution of social capital is shown in Figure 5.6.

Figure 5.6

Social capital (N=350)
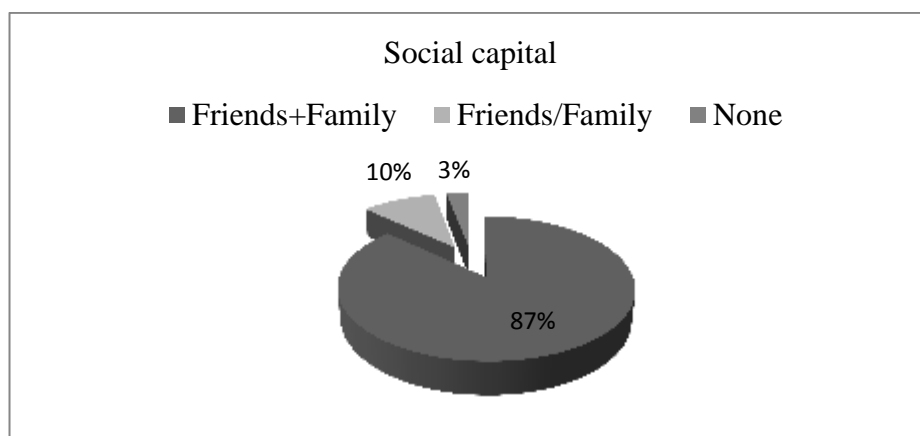
5.4   Descriptive overview of health literacy

5.4.1   Health literacy (HLS-EU-16)

Health literacy was assessed by the scale of Health Literacy (HL-EU-16). Of the respondents 20 % had limited health literacy, 23% had sufficient health literacy, and 57 % had excellent health literacy. The distribution of health literacy levels are shown in Table 5.8.

Table 5.8

Health literacy (N=350)

Health literacy	Frequency	Percentage
Excellent health literacy	199	56.9%
Sufficient health literacy	81	23.1%
Limited health literacy	70	20%
Total	350	100%

5.4.2 Functional health literacy (NVS-UK)

The results indicated (see Table 5.9) that 61% of people had limited functional health literacy, 17 % of respondents recorded possibility of low functional health literacy and 22 % had adequate functional health literacy.

Table 5.9

Functional health literacy (N=350)

Functional health literacy	Frequency	Percentage
Limited functional health literacy	214	61.1%
Possibility of low functional health literacy	60	17.1%
Adequate functional health literacy	76	21.1%
Total	350	100%

5.5 Analysis of relationship between demographic variables

5.5.1 Gender and employment

A Chi-square analysis was carried out to test the association between gender and employment status of the participants. A Chi-square test for independence indicated significant association between gender and employment: $\chi^2(4, n=350) = 97.10$, $p<.0005$, $V=.52$ (large effect). This means that the proportion of the males who work is significantly different from the proportion of females who were employed. This result indicates that 16.9% of the male participants never had a job while 59.6% female participants never worked. The majority of the male participants (28.6%) working 31-48 hours in a week while majority female (15.5%) working hours recorded are 16-30 hours in a week. The breakdown of gender and employment is shown in Table 5.10.

Table 5.10

Gender and employment (N=350)

Gender	Working hours per week					
	Never worked	15 hours or less	16-30 hours	31-48 hours	49 hours or more	Row total
Male	16.9%(32)	7.9%(15)	20.1%(38)	28.6%(54)	26.5%(50)	100%(189)
Female	59.6%(96)	13.7%(22)	15.5%(25)	8.7%(14)	2.5%(4)	100%(161)
Column total	36.6%(128)	10.6%(37)	18%(63)	19.4%(68)	15.4%(54)	100%(350)

5.5.2 Gender and smoking behaviour

A Chi-square test for independence indicated significant association between gender and smoking behaviour, χ^2 (1, n=350) =109.11, p<.0005, *phi*= .55 (large effect). This means that the proportion of the men who smoke is significantly different from the proportion of females who smoke. This result indicates that 51.9% of the male participants smoked while only 1.2% female participants did so. The majority of the female participants (98.8%) do not smoke while 48.1% of the male participants also do not smoke. The results also indicate that the majority of the participants (71.1%) do not smoke in this sample of the South Asian community. The breakdown of gender and smoking is shown in Table 5.11.

Table 5.11

Gender and smoking behaviour (N=350)

Gender	Smoking behaviour		
	Yes	No	Row total
Male	98 (51.9%)	91 (48.1%)	189 (100%)
Female	2 (1.2%)	159 (98.8%)	161 (100%)
Column total	100 (28.6%)	250 (71.4%)	350 (100%)

5.5.3   Gender and diabetes

There were two sample populations in this survey research. Participants with diabetes (n=150) and without diabetes (n=200). A Chi-square test for independence indicated significant association between gender and having diabetes, χ^2 (1, n=350) =13.57, p<.0005, *phi*= .19 (small effect). This shows that men were more likely to have diabetes (51.9%) than women (32.3%). The results are shown in Table 5.12 about gender and diabetes.

Table 5.12

Gender and diabetes (N=350)

Gender	With diabetes/Without diabetes		
	Living with diabetes	Without diabetes	Row total
Male	51.9% (98)	48.1% (91)	100% (189)
Female	32.3% (53)	67.7% (109)	100% (161)
Column total	42.9% (150)	57.1% (200)	100% (350)

5.6   Analysis of relationship between health literacy and demographics

5.6.1   Gender and functional health literacy (NVS-UK)

A Chi-square analysis was carried out to test the association between gender and functional health literacy (NVS-UK) of the participants. A Chi-square test for independence indicated there was no significant association between gender and functional health literacy, χ^2 (2, n=350) =.47, p = .78, V= .03 (small effect) while male and females have no differences in functional health literacy levels. The distribution of functional health literacy and gender is shown in Table 5.13.

Table 5.13

Gender and functional health literacy (N=350)

	Functional health literacy			
Gender	Limited literacy	Possibility of limited literacy	Adequate literacy	Row total
Male	61.9% (117)	15.9% (30)	22.2% (42)	100% (189)
Female	60.2% (97)	18.6% (30)	21.1% (34)	100% (161)
Column total	61.1% (214)	17.1% (60)	21.7% (76)	100% (350)

5.6.2 Gender and health literacy (HLS-EU-16)

The analysis was carried out to test the association between gender and health literacy of the participants. A Chi-square test for independence indicated significant association between gender and health literacy, χ^2 (2, n=350) =10.23, p <.005, V= .17 (small effect). Females' level of health literacy is lower than males' health literacy levels. The distribution of health literacy and gender is shown in Table 5.14.

Table 5.14

Gender and health literacy (N=350)

	Health literacy			
Gender	Limited health literacy	Possibility of limited health literacy	Adequate health literacy	Row total
Male	14.3% (27)	27.5% (52)	58.2% (110)	100% (189)
Female	26.7% (43)	18% (29)	55.3% (89)	100% (161)
Column total	20% (70)	23.1% (81)	56.9% (199)	100% (350)

5.6.3 Age and functional health literacy (NVS-UK)

A Chi-square analysis was carried out to test the association between age and functional health literacy of the participants (see Table 5.15). A Chi-square test for independence indicated significant association between age and functional health literacy, χ^2 (6, $n=350$) $=29.58$, $p <.0005$, $V= .20$ (large effect).This means that there are significant differences across age groups in relation to functional health literacy, older participants were more likely to have limited functional health literacy.

Table 5.15

Age and functional health literacy (N=350)

Age	Functional health literacy			
	Limited functional health literacy	Possibility of limited functional health literacy	Adequate functional health literacy	Row total
20-29	50.7% (74)	17.8% (26)	31.5% (46)	100% (146)
30-39	57.1% (60)	21% (22)	21.9% (23)	100% (105)
40-49	74.5% (38)	15.7% (8)	9.8% (5)	100% (51)
50 or older	87.5% (42)	8.3% (4)	4.2% (2)	100% (48)
Column total	61.1% (214)	17.1% (60)	21.7% (76)	100% (350)

5.6.4   Age and Health Literacy (HLS-EU-16)

The analysis was carried out to test the association between age and health literacy of the participants. A Chi-square test for independence indicated there was no significant association between age and health literacy, χ^2 (6, n=350) = 8.41, p = 20, V=.11 (small effect). This means that there are no significant differences in health literacy level of participants across different age groups. The distribution for age and health literacy is shown in Table 5.6.

Table 5.16

Age and health literacy (N=350)

| Age | Health literacy | | | |
	Limited health literacy	Sufficient health literacy	Excellent health literacy	Row total
20-29	18.5% (27)	24% (35)	57.5% (84)	100% (146)
30-39	14.3% (15)	21.9% (23)	63.8% (67)	100% (105)
40-49	25.5% (13)	21.6% (11)	52.9% (27)	100% (51)
50 or older	31.3% (15)	25% (12)	43.8% (21)	100% (48)
Column total	20% (70)	23.1% (81)	59.9% (199)	100% (350)

5.6.5   Education and functional health literacy (NVS-UK)

A Chi-square test for independence indicated significant association between education and functional health literacy, χ^2 (4, n=350) = 127.89, p <.0005, V= .42 (large effect). This means that there were significant differences across educational qualification of the participants and functional health literacy. Participants with no qualification have limited functional health literacy (93.5%), and participants with qualification have higher adequate functional health literacy (44.1%). The results are shown in Table 5.17, with the educational qualification.

Table 5.17

Education and functional health literacy (N=350)

Education	Functional health literacy			
	Limited functional health literacy	Possibility of limited functional health literacy	Adequate functional health literacy	Row total
No qualification	93.5% (115)	4.1% (5)	2.4% (3)	100% (123)
Partial/some qualification	70.7% (53)	21.3% (16)	8% (6)	100% (75)
Qualification	30.3% (46)	25.7% (39)	44.1% (67)	100% (152)
Column total	61.1% (214)	17.1% (60)	21.7% (46)	100% (350)

5.6.6 Education and health literacy (HLS-EU-16)

A Chi-square analysis was carried out to test the association between education and health literacy (HL-EU-16) of the participants (see Table 5.18). A Chi-square test for independence indicated significant association between education and health literacy, χ^2 (4, n=350) = 57.26, $p <$.0005, V= .28 (medium effect). This means that there are significant differences across educational qualification of the participants and health literacy. Participants with no qualification were more likely to have limited health literacy (36.6%) than participants with qualifications (56.9%).

Table 5.18

Education and health literacy (N=350)

| Education | Health literacy | | | |
	Limited health literacy	Sufficient health literacy	Excellent health literacy	Row total
No qualification	36.6% (45)	30.9% (38)	32.5% (40)	100% (123)
Partial/some qualification	18.7% (14)	22.7% (17)	58.7% (44)	100% (75)
Qualification	7.2% (11)	17.1% (26)	75.7% (115)	100% (152)
Column total	20% (70)	23.1% (81)	56.9% (199)	100% (350)

5.6.7 South Asian ethnicity and functional health literacy (NVS-UK)

A Chi-square test for independence indicated significant association between ethnicity and functional health literacy, χ^2 (4, n=350) = 15.17, p <.005, V= .14 (small effect). This means that the level of functional health literacy was significantly different within Pakistani, Indian and Bangladeshi participants. More participants from Indian ethnic origin have adequate functional health literacy (33.3%) compared to Pakistani (16%) and Bangladeshi (19%) participants. The breakdown for the results of ethnicity and functional health literacy are shown in Table 5.19.

Table 5.19

South Asian ethnicity and functional health literacy (N=350)

Ethnicity	Functional health literacy			
	Limited functional health literacy	Possibility of limited functional health literacy	Adequate functional health literacy	Row total
Pakistani	66.5% (133)	17.5% (35)	16% (32)	100% (200)
Indian	53.7% (58)	13% (14)	33.3% (36)	100% (108)
Bangladeshi	54.8% (23)	26.2% (11)	19% (8)	100% (42)
Column total	61.1% (214)	17.1% (60)	21.7% (76)	100% (350)

5.6.8 South Asian ethnicity and health literacy (HLS-EU-16)

A Chi-square test for independence indicated significant association between ethnicity and health literacy, χ^2 (4, n=350) = 10.20, $p <$.05, V= .12 (small effect). This means that the level of health literacy is significantly different within Pakistani, Indian and Bangladeshi participants and more Indians have excellent health literacy (25%) compared to Pakistani (19%) and Bangladeshi participants (14.3%) see Table 5.20.

Table 5.20

South Asian ethnicity and health literacy (N=350)

Ethnicity	Health literacy			
	Limited health literacy	Sufficient health literacy	Excellent health literacy	Row total
Pakistani	25.5% (46)	55.5% (111)	19% (43)	100% (200)
Indian	13% (14)	62% (67)	25% (27)	100% (108)
Bangladeshi	11.9% (4)	73.8% (31)	14.3% (7)	100% (42)
Column total	20% (64)	59.7% (209)	20.3% (77)	100% (350)

5.7 Correlation analysis

Correlation analysis was performed to analyse the relationship between variables: health literacy, functional health literacy, health status, quality of life and self-efficacy. As there were two sample populations, these correlation analyses were carried out separately for participants with diabetes and without diabetes.

5.7.1 Health literacy, functional health literacy, health status and self-efficacy (Participants without diabetes)

The relationship between health literacy (HLS-EU-16), functional health literacy (NVS-UK), perceived health status, and self-efficacy was investigated using Pearson product-moment correlation coefficient. Preliminary analyses were performed to ensure no violation of the assumptions of normality, linearity and homoscedasticity. There was a strong, positive correlation between perceived health status and other variables. Health literacy and perceived health status has significant positive correlation, r = 0.35, n=200, $p<.001$ (medium effect). Functional health literacy and perceived health status has significant positive correlation, r= 0.35, n=200, $p< .001$ (medium effect). Self-efficacy and perceived health status also showed significant positive correlation, r=0.43, n=200, $p<.001$ (medium effect). There was a strong positive correlation between functional health literacy and health literacy, r=0.48, n=200, $p<.001$ (medium effect). Self-efficacy also had strong positive correlation with functional health literacy, r=0.54, n=200, $p<.001$ (large effect) and health literacy, r=0.43, n=200, $p<.001$ (medium effect), see Table 5.21 (p. 205).

Table 5.21

Pearson correlation among health literacy, functional health literacy, perceived health status and self-efficacy with participants without diabetes (n=200)

	Health literacy	Functional health literacy	Self-efficacy
Perceived health status	.345**	.345**	.430**
Health literacy	-	.479**	.536**
Functional health literacy	-	-	.427**

**P<0.05

5.7.2 Health literacy, functional health literacy, self-efficacy and quality of life (Participants with diabetes)

The relationship between health literacy (HLS-EU-16), functional health literacy (NVS-UK), self-efficacy and quality of life were investigated using Pearson product-moment correlation coefficient in participants with diabetes. Preliminary analyses were performed to ensure no violation of the assumptions of normality, linearity and homoscedasticity. There was a strong, positive correlation between quality of life and health literacy, $r=0.35$, n=200, $p<.001$ (medium effect). The quality of life and self-efficacy also has a significant positive correlation, r=0.38, n=150, $p<.001$ (medium effect). There was a non-significant correlation between quality of life and functional health literacy, $r=0.11$, n=150, $p=152$ (small effect). There was a strong positive correlation between functional health literacy and health literacy, $r=0.43$, n=150, $p<.001$ (medium effect). Self-efficacy also had strong positive correlation with functional health literacy, $r=0.20$, n=150, $p<.001$ (small effect) and health literacy, $r=0.47$, n=150, $p<.001$(medium effect), see Table 5.22 (p. 206).

Table 5.22

Pearson correlation among health literacy, functional health literacy, self-efficacy and quality of life of the participants with diabetes (n=150).

	Health literacy	Functional health literacy	Self-efficacy
Quality of life	.384**	.118	.367**
Health literacy	-	.431**	.470**
Functional health literacy	-	-	.198*

**P<0.005, * P<0.05

5.8 Predicting health literacy and functional health literacy

5.8.1 Logistic regression predicting likelihood of adequate health literacy (HLS-EU-16)

A logistic regression analysis was conducted to predict adequate/inadequate health literacy for 350 South Asians using age, education, gender, income and functional health literacy as predictors. The full model containing all the predictors was statistically significant, χ^2 (7, N=350) = 81.30, *P*< .0005, indicating that the model was able to distinguish between respondents who had adequate and inadequate health literacy. The model as a whole explained between 20.7 % (Cox and Snell R square) and 31.8 % (The Nagelkerke R Square*)* of the variance in the level of health literacy, and correctly classified 84.6% of cases. As shown in Table 5.23 (p. 207) all the predictors except partial qualification were statistically significant.

Table 5.23

Logistic regression predicting likelihood of adequate health literacy (N=350)

Variables	B	S.E	*P value*	Odds Ratio
Age (1)	-.972	.42	.02	.378
Age (2)	-1.398	.59	.01	.24
Education (1)	.576	.36	.11	1.77
Education (2)	1.273	.40	.002	3.57
Gender (1)	-1.072	.30	.000	.342
Income	.303	.14	.03	1.35
Functional health literacy(1)	2.055	1.05	.05	7.08
Constant	1.297	.54		

5.8.2 Logistic regression predicting likelihood of adequate functional health literacy (NVS-UK)

A logistic regression analysis was conducted to predict adequate/inadequate functional health literacy for 350 South Asians using age, education, gender, and income as predictors. The full model containing all predictors was statistically significant, χ^2 (6, N=350) = 116.27, *P*< .0005, indicating that the model was able to distinguish between respondents who had adequate and inadequate functional health literacy. The model as a whole explained between 28.3 % (Cox and Snell R square) and 43.9 % (The Nagelkerke R Square*)* of the variance in the level of functional health literacy, and correctly classified 82 % of cases. As shown in Table 5.24 (p. 208) all the predictors except partial qualification, age 65 and older, and income were statistically significant.

Table 5.24

Logistic regression predicting likelihood of adequate functional health literacy (N=350)

Variables	B	S.E	*P value*	Odds Ratio
Age (1)	-1.87	.37	.000	.15
Age (2)	-1.43	.84	.09	.23
Education (1)	.72	.74	.33	2.05
Education (2)	2.56	.63	.000	13.01
Gender (1)	-.71	.34	.03	.48
Income	.13	.08	.12	1.14
Constant	-2.12	.67		

5.9   Diabetes and quality of life

Participants with diabetes also completed an additional questionnaire about the impact of diabetes on their quality of life. It assesses the overall impact of diabetes on quality of life of an individual and also explored the impact on individual life domains of a person living with this condition.

Participants were asked about their present quality of life. 44% of the participants are satisfied that they are having a good quality of life while 56% of the participants consider they have a poor quality of life (Figure 5.7, p. 209). Another overview item was asked about the quality of life if they do not have diabetes. 68% of the participants thought that their quality of life could be much better if they do not have diabetes, 21% said it could be little better and 11% participants believe that it will remain same and diabetes had made no difference in the quality of life (Figure 5.8, p. 209).

Figure 5.7   Figure 5.8
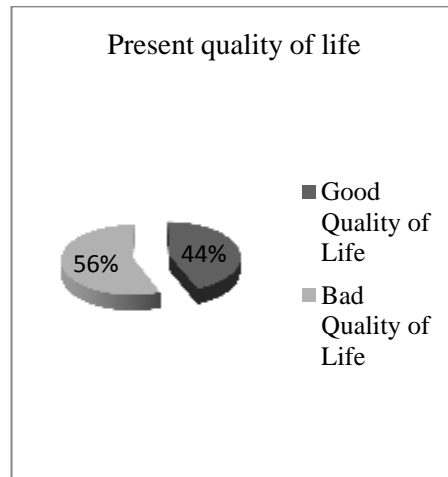
Present quality of life   Quality of life could be without diabetes
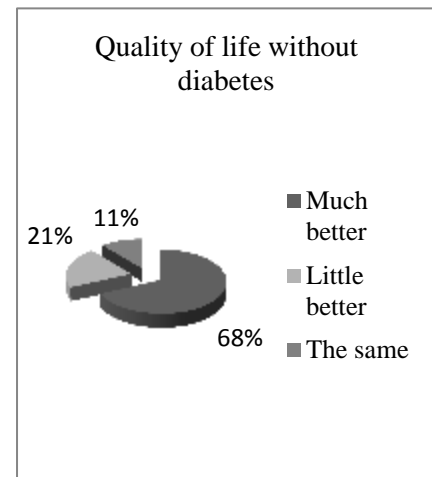
The quality of life scale also assessed the impact of diabetes on individual domains of life

(Figure 5.9, p. 210). It shows the negative impact of diabetes, indicating where most and

least impact occurs for individual life domains. The most affected domain of life is

freedom to eat (Mean=-4.19) followed by freedom to drink (Mean=-3.53). The least impact

of diabetes was recorded on the relationship with others (Mean=-0.57) and the reaction of

the society while living with this condition (Mean=-0.55).

Figure 5.9

Impact of diabetes on quality of life domains (N=150)
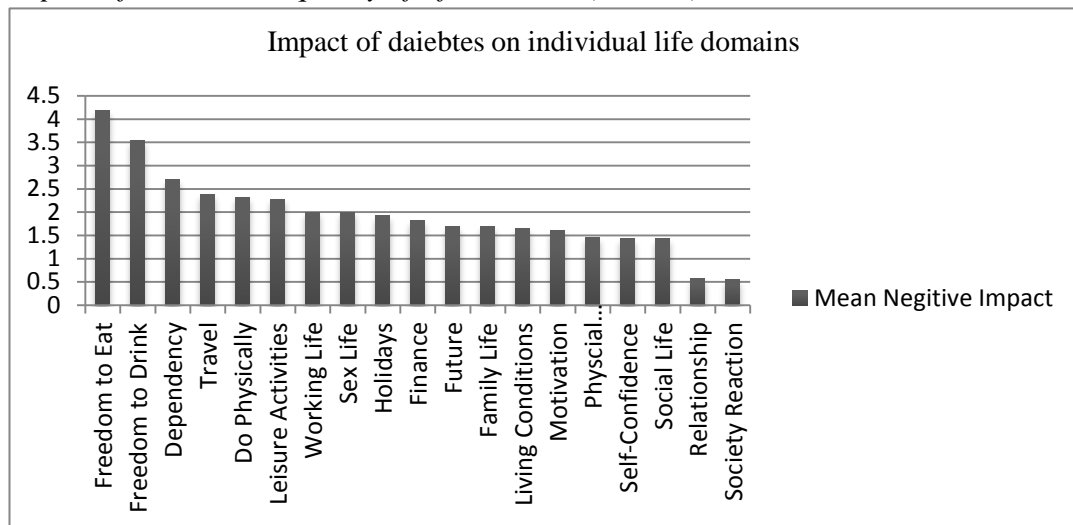
A further analysis was carried out to assess the mean scores of present quality of life, the impact of diabetes and average weighted impact on the life of individuals (see Figure 5.10). It shows the mean score for quality of life (M=0.23), the mean impact of diabetes on quality of life and it shows this condition is negatively impacting on quality of life of the participants (M=-1.57). Average weighted impact shows the negative impact of diabetes (M=-1.73).

Figure 5.10

Overall impact of diabetes on quality of life (N=150)
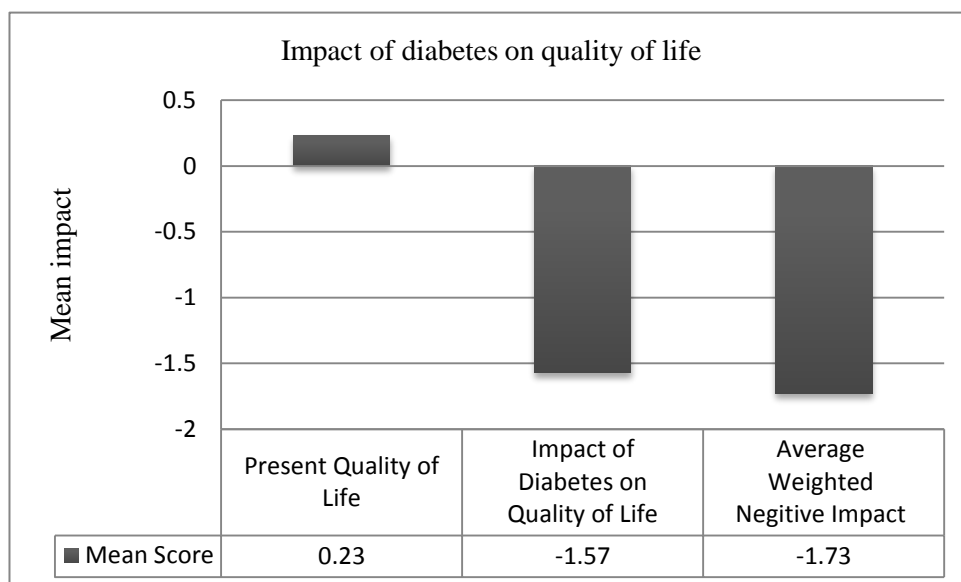
5.10 Discussion

The primary aim of this study was to assess the health literacy of the South Asian respondents, and findings thus suggest concern of health literacy levels in this community. It is important to note here that during the data collection process the researcher's role is considered important as the assistance was provided in translating the questions asked in their native language to improve the efficacy of the response from the participants. Further to minimise the role of English language (questionnaire used were in English language) as study is about examining their health literacy level and not their language ability. Health literacy was assessed by using two different questionnaires designed to examine health literacy. NVS-UK was used to assess the functional health literacy of the people. Results indicated that 61% of this population had limited functional health literacy. The HLS-EU-16 was also used to assess health literacy, and it was reported that 57% of the participants have excellent health literacy while 20% indicated limited health literacy. The difference between the results indicates the different nature of the scales used in this research. NVS-UK assessed the functional ability of the participants as they have to look for the information by themselves while HLS-EU is a self-reported scale that assesses health literacy. These contrasting findings suggest the different nature of the scales used to assess health literacy. Results in present study thus reinforce the statement of Ishikawa et al. (2008) that due to self-reporting mode of the health literacy measures, there might be a tendency to overestimate the health literacy levels of the individuals. However, there was some critic over the use of NVS scale of measuring health literacy for research purposes. For example, Osborn et al. (2007) had some reservation about the use of NVS that is not a good tool for research purposes compared to other scales used to assess health literacy (REALM, S-TOFHLA).

However, unlike the NVS-UK, the HL-EU instrument does not only measure individuals' abilities or skills but also reflects self-evaluated health literacy competencies of populations about health literacy demands of specific national situations. It was further mentioned about the interpretation of the HLS-EU-16 that when interpreting results, group differences may also be influenced by the extent of experience of a given tasks, or by different rating tendencies (to rather understate or overstate difficulties) and by different expectations concerning difficulties of tasks. Therefore the HLS-EU-16 refers to self-perceived measures of health literacy and reflects interactions between individuals' competencies and situational complexities or demands. Both are important regarding enabling people to understand and follow the information related to health care and day to day activities.

Health literacy skills specific to diabetes management includes: reading labels on the pill bottles, following writing and verbal directions, comprehending appointment information, educational brochures, and informed consent documents (Schillinger et al., 2002). Particularly, numeracy is fundamental to diabetes self-management in understanding medication dosage, test results, insulin requirements and interpreting food labels (Osborn et al., 2010). The health literacy evidence in this research (particularly scores on functional health literacy) suggest concern for people with diabetes as part of self-management of this condition. An educational intervention to improve health literacy and self-management skills of the people with diabetes have shown positive results that can empower the patients by supporting them to acquire and use skills through which they can assume responsibility for day to day self-management of their condition. In the UK the National Institute for Clinical Excellence (NICE) has therefore recommended that all the patients with diabetes should be offered structured education and there is a specific education program for South Asians (NICE, 2003). National Framework for Diabetes has

also advocated patient empowerment through education and improved self- management capacities of the individual's (Department of Health, 2001).

Health literacy is the construct that can be determined by the personal, environmental and social factors. The present research has demonstrated that participants' age, education, gender and ethnic status has an association with their health literacy level. Education was considered one of the determinants of health literacy levels in population and health literacy is a keystone in diabetes management too. Two studies conducted by Hawthorne (1990) and Simmons et al.(1991) have shown that people from the South Asian community in the UK know less about diabetes and its management than comparable to white subjects. Present study highlighted 35.7% of the participants that have no education at all and 21.4% have an education below the compulsory level in this sample of South Asians in the UK. Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs (1999) have highlighted that poor functional health literacy is common among people who have low educational attainment and among older people and people belonging to racial and ethnic minorities. Further analysis indicates that levels of health literacy increase with the level of education, but there was another interesting finding that people with foreign qualification also had limited functional and general health literacy.

Both measures show that levels of health literacy decline as participants age increase and previous research have indicated that age is a significant determinant of health literacy level across all people irrespective of ethnicity (Chao et al. 2008). About gender, there was no significant difference between gender and functional health literacy while health literacy measured by HLS-EU-16 showed a significant difference between males and females. Ethnicity is considered an independent factor in determining the level of health literacy of ethnic minorities living in Western countries (WHO, 2013). In this research, the majority of the South Asians have limited functional health literacy (61%),

but as compared to Pakistani and Bangladeshi, Indians had a better level of functional health literacy. These results were consistent with health literacy in general, there was a significant difference between South Asian communities, and Indians having better health literacy as compared to Pakistani and Bangladeshi participants in this research.

Analysis of the demographic data indicates that majority of the participants do not smoke (72%), and there was a significant difference between gender and smoking behaviour. Females smoked less than males comparatively. Alcohol consumption was less in this sample of population and majority of the participants (88.86%) irrespective of gender did not drink alcohol. These can be considered positives with diabetes management as smoking and alcohol consumption can increase diabetes-related complication.

Another significant finding in this study was exercise habits in this population and results indicated an apprehension in this community that needs to be explored a bit further to investigate the barriers to not engaging in exercise. The current study indicated that the majority (50%) of the participants were not doing exercise. Lower physical activity is a well-established risk factor for diabetes, and studies so far conducted on self-reported physical activity levels and suggest that physical activity levels are lower in South Asian adults compared with other groups (Fischbacher & Alexander, 2004). Lifestyle changes in the form of regular exercise and dietary modifications can prevent 58% of type2 diabetes in people at high risk (Lawton et al., 2006). People from the South Asian community are at six times greater risk of developing diabetes as compared to the white population in the UK (Diabetes UK, 2012). Kim et al. (2004) conclude that people with adequate health literacy levels exercise more and even moderate physical activity can improve glycaemic control, improved cardiovascular health, functional status and promoting longevity while living with diabetes (Hay & Clark, 1999). Healthy and balanced diet and exercise are an important part of the diabetes management, and cultural practices have a huge effect on the

life of an individual with diabetes, so there is a need to consider and understand the barriers for not doing exercise in South Asians living in the UK. This builds the rationale for study two in this thesis that will explore the cultural perspective of South Asians in the management of diabetes.

The results of the current study indicated a significant association of self-efficacy with health literacy and functional health literacy which was consistent with previous research (Kim & Yu, 2010; Inoue et al., 2013; McCleary-Jeans, 2011; Sarkar et al., 2006). These significant findings were consistent in both sample groups participants with and without diabetes. However, Jahanlou and Karami (2009) suggested that health literacy levels affect more to the self-efficacy of the individuals with diabetes that is a relevant determinant of the self-management behaviour to manage this condition. Osborn et al. (2010) concluded that health literacy and numeracy skills are associated with greater diabetes self-efficacy.

Results also showed significant positive correlation between health literacy, functional health literacy and health status that was in line with previous research (Bennett, Chen, Sorouri & White, 2009; Osborn et al., 2011). A UK-based systematic review conducted by Easton et al. (2010) provided the evidence about the association between health literacy and functional health literacy with the health status measured through self-reported and by using objective measures. Further another study conducted by Furuya, Kondo, Yamagata and Hashimoto (2013) also reported a significant association between self-reported health status and health literacy levels and further suggested to reduce health inequalities, policy interventions should focus on the promotion of health literacy among people who are at the margin for health literacy capacities.

Results indicated that quality of life is significantly associated with health literacy while there was a non-significant association with functional health literacy of participants with diabetes. There were subsequent studies that suggested that carefully designed self-management interventions the target self-efficacy may be effective in population with inadequate health literacy (Kim, Love, Quistberg, & Shea, 2004., Rothman, Malone, Bryant, Horlen, DeWalt & Pignone, 2004., Gerber et al 2005., Rothman et al, 2004., Sarkar, Fisher & Schillinger, 2006). Rak (2014) suggested that improved self-efficacy may contribute to improved health and employment outcomes of individuals with diabetes. Self-efficacy may be a relevant determinant of self-management behaviours among the population with limited health literacy skills. Osborn, Cavanaugh, Wallston, and Rothman (2010) suggested that diabetes self-efficacy may be an important target for intervention to improve diabetes control and promote health equity related to health literacy and general numeracy skills needed for diabetes management. According to DeWalt, Boone and Pignone (2007) targeting only to improve self-efficacy is unlikely to reduce literacy-related disparities. Therefore, self-efficacy can be a relevant determinant of self-management behaviours among the population with limited health literacy (Sarkar, Fisher & Schillinger, 2006).

Results also indicated a significant positive association between self-efficacy and perceived health status as would be expected from previous findings that self-efficacy considered independent factor for health status (Osborn, Paasche-Orlow, Bailey & Wolf, 2011). Farrell, Wicks, and Martin (2004) described profound positive effects of self-efficacy on health promotion, patient education, clinical practice and patient outcomes. Logistic regression was applied to understand the likelihood of the health literacy levels predicted by the some of the variables. In the prediction of general health literacy; age, education, gender, income and functional health literacy had made a significant

contribution (32%) in predicting health literacy of the participants. Functional health literacy was significantly predicted (43%) by age, education and gender.

In addition to assessing health literacy and other variables, a diabetes-specific quality of life measure, ADDQoL, was also administered to the participants with diabetes (*N=150*). The ADDQoL consists of important domains that may be influenced by diabetes (Sundaram, Kavookjian, Patrick, Miller, Madhavan, & Scott, 2007). The unique feature of ADDQoL is that it takes into account both the participant-perceived impact of diabetes on a domain and the importance of that domain to the participants. The results of the present study indicated that all of the aspects of the quality of life tested were impaired by diabetes to some extent, with the greatest impact observed on the participants' freedom to eat and drink. Similar findings were reported in other studies that examined the quality of life of the people with diabetes by using ADDQoL (Wee, Tan, Goh & Li, 2006., Bradley & Speight, 2002., Shim, Lee, Toh, Tang & Ko, 2012). The impact of the dietary restriction on quality of life is considerable because recommended diet modification usually differs from the participants' typical diet and results in feelings of restriction and stress. Another overview item was asked about the quality of life if they do not have diabetes and 68% of the participants recorded their quality of life could be better if they did not have diabetes.

People with chronic medical conditions such as diabetes have to face many problems which may impact on their quality of life. In general, most studies reported that quality of life among people with diabetes is worse than the quality of life in the general population (Rubin & Peyrot, 1999). Although there is substantial research evidence available about the impact of diabetes on quality of life (Jahanlou & Karami, 2009), there is little research evidence available about the level of health literacy and quality of life with diabetes (Bailey et al., 2014) and in the perspective of minority ethnic communities in the UK.

5.11   Conclusion

The current study has highlighted the significant findings of health literacy levels of the South Asians in the UK. In the past, mixed results have been demonstrated the association of health literacy with diabetes management and self-efficacy while the quality of life is this area has limited or no data available about health literacy. The present study thus reinforces the existing findings along with presenting some novel findings those suggest health literacy levels of the South Asians, and data about functional health literacy suggest particular concern for the participants in this research (61% have limited functional health literacy). Physical activity is considered an important part of prevention and management of diabetes and findings thus far suggest majority (50%) of the participants are not doing any exercise, which increases the significance of exploring potential barriers to physical activity in this community. The quality of life after diabetes also suggest significant findings, the majority of the participants described their quality of life could be much better if they did not have diabetes. Diabetes has a negative impact on their eating, physical capability, working life, and increases their dependency upon others. All these findings open new doors to explore the cultural perspective of the South Asians to increase understanding of health literacy needs and how diabetes management can be improved in this community.

6   Study 2: Exploring Health Literacy through Photovoice

The Photovoice study aimed to explore the health literacy needs of individuals with diabetes in the South Asian community. Each focus group discussion (conducted in native language of the participants) and images taken by the participants were examined in great detail through a thematic analysis approach, before examining more nomothetic general claims across four focus group discussions. The focus of carrying out the detailed analysis was to explore health literacy needs in particular with reference to diabetes management in this community. A narrative account and interpretation of themes that emerged from the analysis were supported with the images captured by the participants and the extracts taken from the participants' accounts. Three superordinate themes arose from the analysis: 1) illustration of self-management in day-to-day life, 2) NHS access and utility in diabetes management and 3) quality of life.

6.1   Theme one: Illustration of self-management in day-to-day life

Health literacy needs, in reference to diabetes self-management, is an important construct to explore because self-management in diabetes demonstrates complex behaviours that require an individual's knowledge and motivation to initiate and maintain necessary changes in food, physical activity, medication and glycaemic control as part of self-management. Under this theme sub-themes related to lifestyle, medical regimes and individual capacities of the participants were discussed.

6.1.1 Sub-theme one: Lifestyle

Lifestyle is one of the most important parts of self-care and management concerning long-term medical conditions. In the case of diabetes, lifestyle can become more important due to relatively higher contributions of physical activity and healthy eating, which can effectively help the management of diabetes. Health literacy was discussed in relation to these two perspectives in this sub-theme, as adequate health literacy can foster healthy behaviours. In this project with South Asians, diet and food were the most discussed area (from both images and narratives) of diabetes management with all the participants. Their narratives and images indicated several themes around diet and eating habits that range from cultural norms and traditions of cooking to eating habits and behaviours. This part of diabetes management was difficult for them as was demonstrated by their discussion of struggle in this area. Participants mentioned the traditional sweets that are rich in fat and sugar as not being good for people with diabetes. Wajeeha took a photograph of one of the South Asian sweets and described it (see Image 6.1).

Image 6.1**:** Gulaab Jamman traditional
sweet (Wajeeha)

"I tell you that in our culture we have a very strong tradition of

sweets. It is an essential part of any event or occasion. It is made of

purified butter and sugar and milk, so it is very high in fat and all

this stuff'' *(Wajeeha, p.39, 1140-1149).*

The account of Wajeeha above, not only reflected the cultural aspect of sweets as a gift but also highlighted the content and ingredients used to prepare this traditional food. With these traditional sweets considered rich in fat and sugar, participants were mainly aware of the unhealthy content of the sweets, and they talked further about the use of sugar and sweets in relation to diabetes. In South Asian culture the common name to describe diabetes is ***"Sugar",*** and a direct link with sugar consumption and the development of diabetes was described by the participants. A dietary change as part of diabetes management was the area that most of the participants were struggling. Ibrar took a photograph of a South Asian snack and shared his story about it (see Image 6.2).

Image 6.2: It is hard to say no! Ibrar

"Yes definitely… sweets do have an effect. And this is one reason

why our people develop diabetes. If you eat sweets, this increases

your sugar level. Like many people in our family they have got so

many problems some have had leg amputations, some have had foot

amputations. So, when you look at them you are taught some

lessons and try to be careful, but even then sometimes you eat what

you should not" *(Ibrar, p.68,1979-1991).*

Diabetes as a long-term medical condition needs a balanced and healthy diet including all nutrients required to maintain good health. However, this stance of management was missing among the majority of participants. Saleem took an image of fresh vegetables and shared his thoughts, which were different from the rest of the participants (see Image 6.3).

Image 6.3: Need to eat healthy

"Most of our people think that they will have diabetes as they have too many sweets. They do not know anything about their diet. They do not care about their meal timings. Eating at a proper time and watching what you are eating is very important" (Saleem, p.85, 2507-2511).

Participants emphasised the content and traditional method of cooking as a risk for increasing weight gain. Their narratives showed that most snacks were deep fried and considered unhealthy. They showed a presence of knowledge and awareness about healthy and unhealthy eating, but this was not necessarily observed in their daily practice. Fatima took a photograph of a deep fried snack and shared her thoughts about this aspect of South Asian food (see Image 6.4, p. 223).

Image 6.4: Deep fried snacks

"Our food also puts us at risk… it increases your weight gain. The

risk is always there that you will become overweight. My father and

I got diabetes, and with diabetes, it is hard to control your weight.

So we should try to avoid fried things, so our weight remains under

control because it is very difficult to control it later on." (Fatima,

p.19, 576-587).

In South Asian culture male participants' reported lower or minimal involvement in cooking in comparison to the female participants. This highlighted the consideration of expected female roles in promoting healthy eating behaviours in the families. This also emphasised the need to improve health-related knowledge not just in the people living with the long-term medical condition of diabetes, but how the involvement of the families in this journey can be effective in this regard. This revealed the concept of the 'distributed health literacy' aspect in which family and friends can help the individuals to become health literate and can act as facilitators to help them follow the advice in managing their health. In this regard, Saleem shared his experience which highlighted how important it is to consider the role of females in promoting a healthy diet.

"Mostly the mothers, sisters, or mother-in-laws may be not

educated, and in some cases, they may not have awareness. If being

a husband or brother, you tell them not to do something they will

mind it, and there will be thought developed on their side that they

do not want to spend money and that is why they say not to do

something. These things will lead to conflict in the families and to

escape this kind of situation you will give up and stop doing

anything. Females need more awareness because they have to

cook… they will do shopping… they have to run the house, so they

have got more things to do within the house" (Saleem, p.99, 2964-

2980).

This stance reported by the male participants was also supported by the female participants in this project. Wajeeha had taken a photograph of grilled food and shared her story of changing her cooking and eating tradition after living with diabetes (see Image 6.5).

Image 6.5: Changed cooking traditions
after diabetes: grilled food (Wajeeha)

"I have changed my cooking tradition since living with diabetes. I

try to have healthy food... because I have this fear in my mind that I

have got diabetes so my children could be at risk of developing it.

So I have changed my cooking pattern...I mostly prefer to bake or

grill food instead of deep frying. I am not using butter or ghee

anymore and use olive oil and vegetable oil'' (Wajeeha, p.45-46,

1297-1309).

Wajeeha revealed the changed behaviour and attitude of a female member of a family who has been diagnosed with diabetes. This self-refection demonstrated a changed insight towards her role of cooking and a diet that needed to be changed to protect her health and her family's health. It highlighted the fact that to improve health literacy at the individual level; it may be beneficial at the individual level to access and comprehend the healthcare information. However, effectiveness through action can be achieved by acknowledging the wider cultural and social norms that need to consider in developing the intervention to enhance the health literacy of families and communities to sustain change.

The provision of luxurious and traditional foods had an important social role in the South Asian community, as described by the participants. It was also a common theme across the majority of the participants that they cared less about the nutritious value of the food and showed more concern towards the presentation and taste of the food. The participants narrated that food is considered a powerful and one of the strongest elements of community identification in the South Asian community. Nasib shared a photograph of a visit to friends (see Image 6.6, p. 226).

Image 6.6: Significance of food in
celebrations (Nasib)

"I try to control what I eat but sometimes when you visit somebody

at their home…they will prepare lots of things for you and then

keep insisting that you have to eat ….. You can have a little, please!

I think they should not do this, because if one person is saying that

he has got a problem and cannot eat… but they keep insisting and

say… no, you have to take a little bit, it will not affect your health.

After eating maybe, you have got a problem, but they do mind it if

you refuse. On these occasions mainly we were given things

like…samosas, pakoras, fried food, kabab etc." (Nasib, p.17, 518-

529).

Participants linked their eating habits and behaviours with their long-standing

habits since childhood. Parveen took a photograph of **paratha** and shared her thoughts (see

Image 6.7, p. 227).

Image 6.7: Efforts to avoid traditional
unhealthy food (Parveen)

"Yes, we need to develop this habit that we do not go for oily foods

from our childhood. A habit can be developed in this regard. Do not

eat highly spicy food. There are certain foods that your body needs

like (i-e protein), so you should have it. We need to have a proper

schedule for everything and then take everything accordingly. There

should be proper times and pattern for food and eating meals"

(Parveen, p.78, 2292-2309).

The participants' narratives also identified some of the lifestyle behaviours and patterns that were considered unhealthy and that there was a need to change these behaviours. Most of the participants recorded that their eating behaviours were not according to the required need of diabetes management. Late night meals, large portions of food and a non-balanced diet was considered some of the common themes across the majority of the participants' narratives. People belonging to young generations were not fond of having this traditional food. They preferred to have fast food (burger, chips) that are also considered unhealthy and can increase the risk of weight gain and trigger related health problems. Participants identified their understanding about the late night eating and its effects on their health. The majority of the male participants also related their eating habits to the conditions of their jobs and expressed a lack of control when it came to their unhealthy eating behaviour. Zafar took a photograph of a meeting at his workplace and

related it with his story of the struggle to manage healthy eating due to his job's demands (see Image 6.8).

Image 6.8: Efforts to adopt healthy
food options (Zafar)

"We try to pick healthy options for eating. Because eating is

also linked to your job as well if you have got an easy job that

makes it possible to manage. Otherwise, it is really difficult.

For example, if you are in a meeting or you are away

somewhere then it is difficult for you to prepare healthy meals.

So then you try to have quick and easy cooking options to save

your time (Zafar, p.96, 2863-2872).

The analysis indicated that people from this community have different standards for measuring the quantity of food, and are less likely to calculate the calories in the food they were eating. Saleem took a photograph of wholemeal bread and discussed this aspect in his narrative (see Image 6.9, p. 229).

Image 6.9: Healthy food options
(Saleem)

"Our people do not know about calories. They will say I have

taken two samosas… half a plate of sweets.. they do not know

how many calories were in that food. In this way, if there is a

wholemeal food option or white metal that will be equal, more

or less" (Saleem, p.93,2759-272767).

The majority of the participants shared their experience of using food as a treatment element for diabetes that was proving effective. Participants shared food as a traditional and authentic treatment element that had been in use for many generations in their community. This also highlighted the need to consider the cultural construct in defining and studying health literacy, as beliefs about health and illness can be influenced by cultural norms and attitudes. Participants shared their experience of using ***"Karaila", "Oakra"*** and ***"Neem"*** as part of treating diabetes and considered it effective. Tayab took an image of '***Oakra'*** and shared his experience in this regard (see Image 6.10, p. 228).

Image 6.10: An effective way of using
Oakra (Tayab)

"Oakra can be used in a way that is really effective in managing

diabetes. Pieces of Oakra are dipped into a glass of water at

night, and the water is drunk in the morning. It can be used as a

cooked vegetable, but it should not be overcooked. Slightly stir

frying it proves effective in managing diabetes. Sometimes I also

missed my medicine, but the use of Oakra extract in water covers

it. However, it should be fresh because if it is not fresh, then it

will not be very effective" (Tayab, p.131, 4032-4041).

Exploring lifestyle habits and physical activity was another important lifestyle construct in the management of diabetes. The majority of the participants were aware of the importance of physical activity in diabetes management. This awareness was primarily raised by their healthcare professionals. This indicates an important aspect of gaining knowledge about health-related issues in this community through face to face interaction with the healthcare professionals. However, health messages regarding exercise had been clearly received, but few of the participants acted upon this lifestyle advice as a part of the diabetes management. Abid took a photograph of an exercise machine and shared his understanding (see Image 6.11, p. 231).

Image 6.11: Exercising equipment is not a
guarantee of doing exercise (Abid).

"I will tell you about exercise.... and this is also advised by the

doctor that you should exercise 30 minutes for five days a week. I

should walk or do any other form of exercise because it is very

useful" (Abid, p.133, 4099-4103).

Abid's account above clearly reflects the understanding about the importance of

physical activity and the expected level of physical activity to commit to. However, what

he was doing differs from his knowledge. Narratives also showed one similar theme across

the majority of the participants that they described the physical activity as a 'should do'

instead of doing it. The relationship between knowledge and expected behaviour was

inconsistent. This shows that to have the knowledge and have adequate health literacy does

not guarantee the changes in health behaviours for all people. The need to consider the

mediating factors are highlighted, especially as they can have the effect of shaping

behaviour that can be described as motivation, as well as shaping environment and cultural

values. For example, female narratives showed that their lives as females revolve around

their family and children. This reflects the cultural gendered practices and their

commitment to family preferences. This also reflected the need to highlight awareness

about attitude and behaviour towards the demands and roles of life, as taking care of others

would not stop you from taking care of yourself. Wajeeha took the following photograph

of her kitchen and related her story to it (see Image 6.12, p. 232).

Image 6.12: The expected role of being
female (Wajeeha)

"I think our lifestyle and living conditions also matter if I talk about

life as a housewife; her thinking always revolves around the

home..... How and what to do? In between, she finds some leisure

time, but she would not think to go out and take a walk or anything

like that. She would prefer to sit on the sofa and watch telly... and

this is very common in our people..... Maybe you can say this is due

to ignorance... that we do not have much awareness about the

importance of physical activity.... the difference of

environments............culture also matters... so all these things

matter a lot" (Wajeeha, p.35,1033-1051).

The majority of the participants did not prioritise exercise as a part of diabetes management. Zafar was the only participant who shared his feelings of guilt as he was unable to do the needed level of physical activity as part of diabetes management. His account reflected that despite the guilt of not being physically active, he was unable to control his life circumstances (see Image 6.13, p. 233).

Image 6.13: Feeling of guilt of not doing exercise (Zafar)

"I feel guilty in this regard...because work and life are not balanced. I tell you that my workplace is not far away from my home, and I can walk but if you have to go on to another commitment after finishing one thing that makes it impossible to manage it by foot. So, all these things are self-produced... and the other thing is that you get stuck in all these things and the surrounding environment, you want to get away from it but you can't" (Zafar, p.95, 2840-2850).

Zafar's account above reflects the lack of control on life circumstances to achieve the desired goal of being physically active. This also draws attention to the fact that if participants try to change their lifestyle choices they can gain that control back in their lives. Only two of the participants recorded their daily routine and habit of regular physical activity as part of changed behaviour after diabetes. Ibrar took a photograph of him walking and shared the account of his changed routine after living with diabetes (see Image 6.14, p. 234).

Image 6.14: Planned efforts to increase
walking after being diagnosed with
diabetes (Ibrar)

"I used to do exercise. I am used to walking five to six miles each

day... like five to six days in a week. When I go to work, I used to go

by foot, and on the weekend I go to the park walk for about 45

minutes. I am just walking and not doing any other exercise"

(Ibrar, p.72, 2102-2109).

Walking and swimming were considered the suitable exercise option for the

majority of the participants. Many respondents pointed out that their active routine in their

jobs provided a substitute for physical activity or exercise. Both the female and male

participants had the same stance towards physical activity at work. This also reflected the

cultural tradition of being active in the day to day activities in comparison to the structured

physical activity traditions of western society. Parveen shared his account of activity

carried out at work which she views as a substitute for physical activity.

"I am not doing any exercise. At my workplace, I have to use the

stairs quite a lot so that t is the physical activity I am used to"

(Parveen, p.75, 2211-2213).

Whether participants had engaged with regular or irregular physical activity as part

of their diabetes management, they acknowledged the positive effect of physical activity

on their blood glucose level. Abid took a photograph showing him running on a treadmill and shared his experiences of the positive effects of exercise habits (see Image 6.15).

Image 6.15: Positive effects of
exercise (Abid)

"A good thing is when I do physical activity. For the next two days,

I feel really good, and sugar (all the participants used this word to

describe diabetes) also remains under control. However, the next

day when you are not doing (exercise), it (Sugar level) gets worse

again" (Abid, p.133-134, 4103-4110).

Abid's account above clearly reflects the positive effects of doing exercise in diabetes management. It also reflected the inconsistency in continuation of exercise habits. When the further barriers to physical activity and exercise were explored, the majority of participants referenced cultural norms and tradition in their narratives on structured physical activity. There were some factors that were linked to the participants intrinsic self while the majority linked exercise with extrinsic factors. A lack of time, being lazy, tiredness and sedentary behaviours in lifestyle were the most mentioned reasons for not doing physical activity. Tayyab took a photograph of the inside of his home and shared his narrative about why physical activity is less common in the South Asian community (see Image 6.16, p. 236).

Image 6.16: Inactive leisure time activities
(Tayyab)

"One major reason is that we are lazy... we do not do exercise. In

work, we would think to only work for two more hours. We are not

used to going for a walk outside and do not take our children out as

well. If my wife got diabetes, she would also stay at home and

would not go out for some physical activity. As her husband, I

would also never encourage her to go out for some physical

activity" (Tayyab, p.136, 4184-4192).

The Participants' narratives indicated the impact of migration on lifestyle habits, especially on physical activity. One of the participants attributed his lack of physical activity towards a reduced walking habit in the UK. For example, cars are considered to be a dire need even for short distances, which is in opposition to common behaviour in their native country. The participants' narratives also explained the complexity of factors that had an effect towards starting and sustaining physical activity. Changes in weather conditions, long-term developed habits and the economic pressure of the extended family in their native country, as well as family responsibilities in the UK, had a combined effect on the health behaviours of the participants. Umer took a photograph of his back garden to reflect the socio-economic aspect of his life (see Image 6.17, p. 237).

Image 6.17: Economical strains to
improve living conditions (Tayab)

"If you are in Pakistan, one person is an earner, and 12 members

of the family are just eating, but you have no tension over there.

You do not have mental tension. In the UK you have mental tension,

and you have to work each day. So, this socioeconomic factor is

very important, and it limits you, and you can't carry on with it

(exercise) on a regular basis" (Umer, p.135, 4153-4161).

Cultural identity was the pervasive theme across all the participants' accounts, irrespective of gender. The lack of a personal habit to do physical activity attributed towards the lifestyle habits of being South Asian. It also showed a lack of flexibility in changing longstanding lifestyle habits; even in the face of severe threats to health. This fatalistic attitude was common across the majority of the participants. It also reflected the complex interaction of personal, social, cultural and economic factors that act as barriers to physical activity. Many participants described various health complaints, such as asthma, painful knees, swollen feet, backache and breathlessness, which all act as barriers to pursuing even simple activities, making things extremely difficult. Participants' narratives also indicated inadequate levels of self-efficacy regarding sustained physical activity when it came to managing diabetes. As discussed earlier, participants have a clear understanding

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of the importance of the role of physical activity in managing diabetes and experienced positive effects after engaging in physical activity. However, they were unable to sustain physical activity. Saeed took a photograph of the park and shared his thoughts about it (see Image 6.18).

Image 6.18: External factors and their influence on personal behaviour (Saeed)

"One day I took my child to the park...the weather was very good. There was the sunshine, and I was feeling very good. I promised myself that from now I would come every day to go for a walk here and my child will also have a chance to enjoy the park. The next day it was raining, but I was still very determined that I had to do it, come what may happen... However, the next day I could not go. Sometimes we make plans but when the time comes to act upon that plan we failed, and everything passed like as usual" (Saeed, p.41, 1208-1220).

Umer, another participant, described it differently. According to him, this was not an issue of motivation but rather an issue of the wider social determinants that also have an effect on the adoption of healthy choices in life (see Image 6.19, p. 239).

"So this socioeconomic factor stops you there... it does not mean

that we haven't got the motivation. We want to act, and we

acknowledge the positive effects of swimming on the body but this

socioeconomic factor limits you to keep carrying it on" (Umer,

p.134, 4119-4125).

Wajeeha, a mum of three, attributed a lack of physical activity in adults due to less exercise habits practised since childhood. She emphasised the role of parents in this regard to raise awareness and provide a suitable environment for children to become more physically active. Wajeeha took this photograph of her son to reflect on this issue (see Image 6.20).

Image 6.20: Inactivity among
children (Wajeeha)

''In children, it is very common to play video games and

things like that. They don't bother to play games that involve

physical activity. In this regard, the parent's role is also important

to become a role model for their children and make them

physically active. The father should play outdoor games... football

and many other friendly games that can be played. You can take

children to parks giving them fresh air and making them

physically active. You are doing the same things; your children

are doing the same things... so it is going on and on" (Wajeeha,

33, 967-983).

Zafar suggested the adoption of a collective effort (group activity) to increase motivation for physical activity.

"In this regard I want to say that if there it would be good if there

was some kind of group activity available that can encourage you

to walk more frequently because collective activities might be more

effective and easy to sustain.... so if there are small groups then that

can increase 70-80 % participation from the people" (Zafar, p.95-

95, 2851-2856).

The suggestions that were given to improve physical activity thus suggest more robust initiatives within this community. Wajeeha was concerned about the physical activity level of children that highlights the need to have a habit of physical activity from childhood. On the other hand, in the case of adults, a collective group effort was considered another strategy that might enable individuals to stick with such lifestyle changes like physical activity.

6.1.2   Sub-theme two: Clinical measures of self-care

Living with diabetes produces the demands of having to take a regular intake of medication and monitoring blood glucose levels to ensure effective management. Medicine was considered a core component of diabetes management among the participants. Amongst their perspectives of clinical measures of diabetes care, blood glucose monitoring was another indicator of effective self-management. Under this theme, the medicine intake and bold glucose monitoring were discussed in accordance with the narratives and images of the participants.

It was reported by all of the participants that they should be careful in taking their medicines regularly. Participants had the knowledge about the importance of medicine in managing diabetes, but they struggled to maintain a regular intake of medicines as part of their diabetes management. Salem took a photograph of his medications and shared his story about it (see Image 6.21).

Image 6.21: The struggle to manage
regular intake of medications

"... Like I tell you about myself, there are 2-3 medicines I have not

taken since last month. I don't bother to take medicines on time... I

don't bother about having meals at proper times. So the balance is

out of control. If the timings are not accurate, then the medicines

will not be effective" (Saleem, p.105, 3158-3176).

There was one participant who shared his thoughts about the different treatment options available to manage diabetes. This particular account of the participant reflected the information and awareness that empowers individuals to make the right decision and make an informed choice when treating medical conditions. Ibrar shared his photograph of medicine and talked about his experience (see Image 6.22).

Image 6.22: Metformin: An effective drug for
diabetes (Ibrar)

"I have a controlled and balanced diet to manage diabetes at the

start. But now I have started taking medicine; it is half of an

80mg tablet that I take in the morning and the other half I take in

the evening" (Ibrar, p.73, 2139-2143).

Participants were aware of the side effects of the medicines, and they have the insight to discuss these issues with healthcare professionals. Medicine as a treatment was considered more accepted while the use of insulin as a treatment option was associated with a worse condition and lack of control with diabetes. Parveen talked about it.

"I am taking Metformin and just taking this medicine. But it is

like this, sometimes it suits you, and sometimes it doesn't... In

that case, you go to the doctor, and they can change the

medicine for you. But if you don't care and your diabetes gets

worse then you have to go for insulin. So for that, you try to have

control over the condition as you do not want to lose the control.

But sometimes your internal conditions are like this, whatever

you do it can become worse" (Parveen, p.72-73, 2120-2138).

The account mentioned above reflected the experience of the individual living with diabetes. She sounded like she had control of her condition with the help of the health care professional. The persistent and continues discussion about the suitability of the medication in keeping diabetes under control reflects the struggle of living with chronic medical conditions. At the same time, the participant also had a fear of losing control with her condition. Due to the long-term demand of the chronic condition participants were struggling to maintain a regular intake of medications. Zafar shared his suggestion about using the photograph of the complications caused by diabetes on the packaging of medicines used to treat it to act as a reminder not to miss doses of medicine.

"I was thinking about one thing like there could be a

photograph of affected people on the packet of cigarettes. There

should be this kind of advertisement on the packets of the

medicine for diabetes. So people who intentionally ignore or

don't know the complication associated with diabetes become

aware and take care of themselves in a more effective manner"

(Zafar, p.89, 2639-2652).

Participants also discussed taking alternative medicine for treating diabetes. They reported that alternative treatments were less effective, but they still use these methods as a treatment option for diabetes. All the participants had their religious beliefs and used their spirituality as a way to handle their health problems. One of the participants shared that he quit smoking once he grew a beard, feeling obliged not to smoke after having a beard. It showed the power of his religious belief and that it could be used to enhance healthy behaviour and better management of diabetes. Umer shared his spiritual way of handling the stresses of daily life. He took a photograph of his car's steering wheel and shared his story about it (see Image 6.23).

Image 6.23: Use of spiritual belief to
manage diabetes (Umer)

*"I put an imagination on the monogram sign in between the steering wheel of the car. I concentrate there and recite some sort of religious verses that mean 'be patient'. I give some sort of self-suggestion to myself that everything is out of control and there is only the creator **(ALLAH)**, and he just can do anything for you."* (Umer,p.128, 3912-3919).

Blood glucose level monitoring was also an important area of diabetes management. It was narrated by the majority of participants that they did not check their

blood glucose levels on a regular basis. The participants described that they normally have

their blood glucose monitored by their healthcare professionals after their appointment

every six months or so. Some of the older participants shared their experience of their

children checking their blood glucose levels as they did not know how to check it by

themselves. It also indicated the support they have inside their families, helping them to

manage their condition. This also highlighted the community resources in any particular

community that should be considered in delivering information for managing long-term

medical conditions. In this case, the inclusion of family in the management process can be

helpful.

According to the participants, blood glucose monitoring depends on the severity of

the diabetes condition and what kind of treatment option you have to manage it. Nasib

shared his photograph of his daughter checking his blood glucose level and shared his story

(see Image 6.24).

Image 6.24: Support from family in
monitoring blood glucose (Nasib)
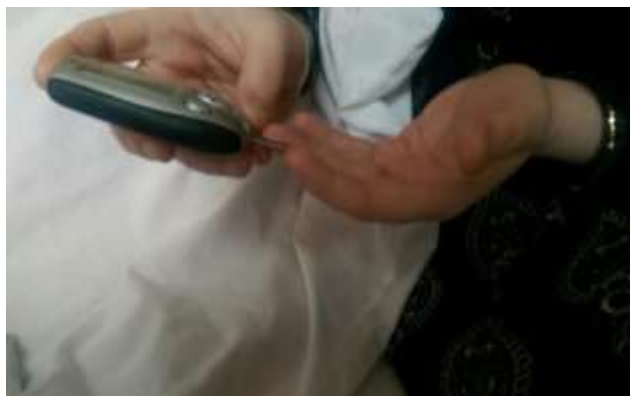
"I do not check my blood glucose level by myself my daughter

checks it for me. Some people are like this they have to check

their blood glucose level and then have the injection as one of

my relatives is used to doing it like this" (Nasib, p.3, 52-57).

Although the participants showed awareness about the significance of blood glucose level monitoring, it was not visible in their self-management plan. There was only one participant who was regular in checking his blood glucose level. Ibrar took a photograph of his blood glucose results and talked about it (see Image 6.25).

Image 6.25: Level of blood glucose
reassures diabetes control (Ibrar)

"I have a machine for sugar checking and used to check it after every five days. If it is around seven then I thought OK it is alright. So sometimes it is 7, 6.8 or 6.5 so it is like this, and it is alright. If it is above that, it might be a concern" (Ibrar, p.72, 2114-2119).

The majority of the participants shared their experiences of assessment of blood glucose level through their inner sense that lets them know about their condition. It reflected the experiential journey of the people living with chronic medical conditions that can be valuable in taking into account how to develop the management plan for individuals living with long-term medical conditions. Although it did not undermine the objective assessment of the blood glucose level, it does reflect the first-hand experience of the individual and how to address the symptoms and signs that need immediate attention while living with this condition.

6.1.3   Sub-theme three: Personal capacities/skills

This theme highlights some of the behaviours that need to reflect back into this community for them to manage their health in a better way. A lack of readability of health-related information, limited knowledge of scientific terminology, and reduced motivation to be part of the research activities are considered some of the things that need to be changed. According to the participants, education has a very powerful role in determining all of these behaviours. Education can increase the use of alternative sources of information in managing their health; increase their motivation which is helpful to the individual for taking control of their life. Participants' accounts also suggested that the majority of the participants not read the information leaflets provided when they got their medicine. Limited use of written information provided in different forms and sources and raise the concern about the appropriateness of the information provided to the participants belonged to this community. The main source of information was considered to be through face to face conversation with the healthcare professionals. This was due to participants having difficulties in understanding the information in the English language. However, they could also ask for help from family members who could read and understand English. This again reflected the community resources that can be utilised to develop the health literacy (family support) of the participants that may not gain the knowledge from the conventional mode of health information. Some of the participants used to ask their children to read the leaflets for them, or they simply did not want to read the information leaflets. When the reason why they did not read the information leaflets was explored, it was narrated that if they read the side effects of the medicine, they would not be able to take medicine. This showed their understanding about the health information and how they use it to make themselves feel empowered about managing their condition in an informed way.

"Children can read the leaflets given with the medicine. But you

know if you read about the side effects you will not be able to

take medicine. I didn't take my medicine twice then doctor got

really angry with me" (Nasib, p.12, 336-339).

The participants expressed that people from the South Asian community might struggle to express their concerns and issues to the health care providers. The concern raised by the participants should be taken into account by the healthcare professionals in their communication, especially when talking to people who might struggle to express their health needs. This has raised concern for a greater consideration of health literacy levels within the healthcare context to maximise the reception of effective care. Saeed, one of the participants, reflected upon this.

"For example, people may have limited knowledge of the disease

and be unable to express the problems in an effective manner. So

the doctor should have this awareness that the person is coming

from a different situation and from another community. They

should consider the background knowledge of the person and

should provide information accordingly" (Saeed, p.57, 1694-

1702).

Participants also reflected upon the organisational skills needed to seek help and information for managing their health. It was also highlighted by the participants accounts that people should have knowledge and awareness about their rights concerning health-related matters. This particular participant reflected upon the development of the health literacy skills and how to be an empowered consumer for health services. He was not aware of the health literacy concept and what skills were included in the definition of the

health literacy, but his narrative highlighted the same concept that shows the definition of health literacy on the skills of individuals:

> *"People should know their rights that they should go to the*
>
> *doctor and ask for any information they need for their health.*
>
> *There is a need to create a sense of responsibility that you are in*
>
> *charge of your health and you can do whatever you want to do*
>
> *for your health. If a person is not motivated nobody can do*
>
> *anything… neither a doctor nor any other NHS staff"(Saleem,*
>
> *p.85, 2520-2527).*

Participants who were used to reading the health-related information from different sources did not consider it their responsibility. They might be used to doing this as a reaction and as a means to avoid the negative attitude of the healthcare professionals. It indicated the need to raise awareness within the community that people need to acknowledge their sense of self-responsibility in taking good care of their health. On the other hand, it also highlighted the structural issue within the healthcare system that should be more health literate. The health care professionals should consider these issues and deal with them accordingly.

> *"Now I am used to checking on the internet before going to the*
>
> *doctor like if I got an infection, I would drink cranberry juice if*
>
> *got fever I will take paracetamol and things like that… you know*
>
> *if you go to the doctor they will say you don't need to come to us*
>
> *for this so it seems that I have not got any problem at all… to*
>
> *avoid that shame I would prefer to stay at home and do*
>
> *something by myself. Once I went to the doctor and told him that*

I am felt dizziness my hands were shaking, I think I am anaemic.

As I had the same problem last time… but the doctor responds to

me like this 'how you can tell without blood test that you are

anaemic? Like they do not appreciate if you have read something

and wanted to share it with the doctor" (Fatima, p.25-26, 784-

815).

Limited readability of health-related information was also narrated by the majority of participants. They did not bother to read the written material related to health and the product labels before buying items. In this case awareness about the importance of reading the product labels and written information is important while living in developed countries where written information is a major source of provision of information related to health and all other areas of life. Saeed took a photograph of the information leaflets and shared his views on it (see Image 6.26).

Image 6.26: Limited utility of written
resources (Saeed)

"I will tell you one thing about when I visit the surgery. There is

a cupboard full of leaflets related to different health-related

information. I tell you that I never picked up anything from there

and I never saw anybody from our community picking up

anything from there… the reason is that we do not have this

concept of self-study about health-related information" (Saeed,

p.52, 1529-1544).

Education was one of the major determinants of the health literacy skills. People with less or no education struggled to follow the instruction properly or were unable to follow. Parveen shared her thoughts about the role of education in managing health. In this case, the use of alternative sources needs to be considered.

"Like some people who are not educated and they found it

difficult to follow the instructions given by the doctor. So the

doctors have to force them to follow the given instructions. As

far as medicine is concerned, they can follow it, but other

changes that are needed as part of diabetes they might not

follow, like exercise and diet pattern and they may need more

information" (Parveen, p.71, 2072-2083).

Ibrar mentioned the use of the internet and other social media sources to look for information on managing diabetes. He was doing this as a part of his self-responsibility in managing diabetes as he narrated about why we waste the time of the doctor when we do not need to. Further participants also shared their thoughts on the fact that people of the South Asian community do not bother to take part in the research activities related to health. This lack of interest attributed towards a lack of awareness about the significance and importance of the role of research in health promotion and maintenance. Although it attributed towards a lack of awareness, Saleem took a different stance towards it. He shared his thoughts about this aspect (see Image 6.27, p. 252).

Image 6.27: Use of internet for health-related
information (Saleem)

"We do not try to get information from somewhere.. if we have

some kind of information, then it is alright, and if we do not have

any information even then, it is alright. It seems equal to us. If

we do not take our matters seriously and we do not ask for help

and advice, nobody will come and give us help at our doorstep.

In some cases, if we have information in our homes even then we

do not pay attention and do not take things seriously" (Saleem,

p.86, 2530-2538).

People who are not native speakers of the English language may find it difficult to express their needs to the health care professionals, and they may not be able to follow the information received. Language can also affect the navigational skills of the people with limited or no English language ability. Participants also shared their concerns about the tradition of getting help on demand within the healthcare sector and how people with limited language ability might hesitate to ask for help. Fatima shared her concerns on this issue.

"Like people who cannot read and understand the English

language they can have problems as they do not know where

they can go and find the relevant information. They do not know

where they can ask for help because when you ask for help, then

you will have… if you are not asking you will not have the help.

Like if there are patients like this then healthcare professionals

should give more information to them if they have any problem

you should guide them" (Fatima, p.23, 704-713).

Participants shared their thoughts about the translation of health-related leaflets in the native language of the people. It can increase the access and use of the health information of the people who have limited or no English language ability. Wajeeha took a photograph of translated information in the Urdu language and shared her thoughts about it (see Image 6.28).

Image 6.28: Looking for information
in native language (Wajeeha)
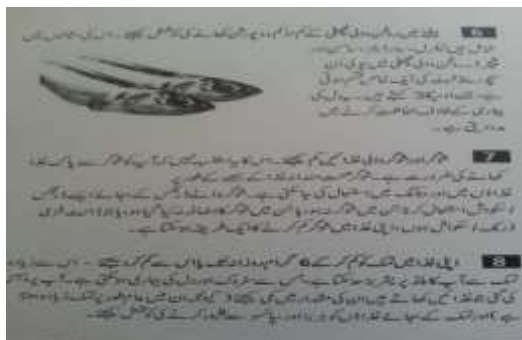
"If you have the information in your own language then it is easy

for you to understand. There are a lot of people in our

community that don't know the English language or they are not

educated enough. So they have this problem that they are unable

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to read information in the English language" (Wajeeha, 34, 999-

1010).

The majority of participants mentioned language as a barrier. However, there were

two participants who agreed that language was not a barrier anymore. They narrated their

views that people from the South Asian community were living here as a second or third

generation, so language may not be considered a barrier anymore, and if it was a barrier,

people could take their children or any other family member with them to the health care

settings as an interpreter.

> *"I don't think language can be a barrier if some people don't*
>
> *know English they can take their children with them to the*
>
> *doctor. People are managing it, and there is no problem like this*
>
> *anymore"* (Ibrar, 70, 2042-2047).

There were different needs that were highlighted through the narratives of the

participants about a lack of readability of written information, and navigational skills also

raised concern. Mainly language was considered the biggest barrier to the effective use of

healthcare information and services. However, the participants also mentioned that the use

of other people's skills in their community and particularly English language proficiency

could be used for mediation in reaping the benefits of available resources. By looking

towards their social networks and families to access and utilise the resources, they could

help to manage their condition.

6.2 Theme two: NHS access and utility in diabetes management

Health literacy is not an individual construct and not the sole responsibility of the

individuals. It is also important to consider the suitability of the material used in health

care, the difficulty of the tasks required by the people, the professionals' ability to communicate effectively to patients, and the overall complexity of the healthcare system. Under this theme, the important issues related to health literacy within the health care context were discussed.

6.2.1   Sub-theme one: Access and use of healthcare services

Participants narrated their experience about the access to the primary health care services, and it was considered easy to approach by all of the participants. Zafar took the photograph of a primary care centre and narrated his experience about the use of primary care services in managing diabetes (see Image 6.29).

Image 6.29: Access: easy to access (Zafar)

> *"Primary care centres are really good facilities and provide easy access for the community. You can see your GP and nurse there; you can discuss your problems, review your prescription. It is walking distance, and they are very clear in providing services to improve your health. The pharmacy is also near so you don't have to go far away it is all easy to manage" (Zafar, p.81,2369-2378).*

Participants were happy with the geographical location of the primary care centre; however, the majority of the participants recorded their thoughts about the difficulty faced in booking an appointment in the morning and the need to be available for the specific time allocated to book appointments. They have recorded their views about the timings for booking appointments in the morning. Wajeeha took this photograph of her mobile phone to reflect her difficulty in booking an appointment (see Image 6.30).

Image 6.30: Digital barriers in accessing
healthcare services (wajeeha)

"If you are unable to have an appointment in the morning on the

same day and you go to the doctor and.... you say please can I

have an appointment for any next day? ......they are used to

saying 'sorry we are fully booked now for the next three weeks'"

(Wajeeha, p.39,1153-1166).

Participants described that timings for booking appointments were not suitable for the majority of participants as they have to manage other life demands (e-g; dropping children off at school and going to work at that time). It was suggested by one of the participants that this problem can be solved by giving an option to book appointments online. On the one hand, this reflected their opinion about the provision of services suitable for people with jobs and other responsibilities. This also reflected the lack of awareness of

the already available services within the NHS. As there was already an online option

available for booking appointments. It also highlighted that there was a limited amount of

digital health literacy to navigate the complex healthcare system within developed

countries. Despite the availability of different sources and services people did not know

about them. Within the context of different healthcare settings, a lack of publicity was

shown in regards to the different options that people could access. Participants also

reported a limited time slot given for appointment consultation and this created

dissatisfaction in discussing the health-related matters with the healthcare professionals.

Fatima shared her experience in this regard:

> *"Our doctor has put on the board that appointments will be for just*
>
> *10 minutes. You can just discuss one problem at one appointment.*
>
> *Like once I had this experience that I had pain in my ear. Then in*
>
> *my throat and I also got a fever when I started to talk to the doctor*
>
> *he said stop! You can just tell me one problem. I can't handle all of*
>
> *these problems. I felt somehow surprised that I had to stop talking*
>
> *about problems that are similar" (Fatima, p.24, 729-748).*

Participants felt that their problems might not be understood well by the healthcare

professionals because they felt bound according to the criteria set by the doctor and not

according to the needs of the individuals. Participants also mentioned about the provision

of the different services in maintaining and promoting the health of the people. There was

only one participant who accessed the lifestyle services to lose weight. This also reflected

that just because people may have an awareness about the services within the community

and NHS they still may not use them. There were different opinions from the participants

about the reduced use of these services because of a number of factors, including economic

strains, cultural norms and job conditions. Nasib recalled his experience about the utility of services.

> *".....Yes, I go for an annual check-up. They send letters as well.*
>
> *Recently I had an eyesight check-up. They provide good care. I had*
>
> *a check for feet, eyesight, so they care about all these things. Some*
>
> *people say the care is not good here, but I used to say no there is*
>
> *good care for diabetes. They do check the nails as I have got*
>
> *problems with my fingernails and it is getting worse" (Nasib, p.11,*
>
> *294-308).*

Educational programs are considered one of the ways to improve self-management of the people living with long-term medical conditions. There was only one participant who shared her knowledge and awareness about the structured education programme provided for people with diabetes. Although she was unable to attend, she believed that attending the program might be effective in managing diabetes. Parveen shared a photograph of her medical form and described her story of using the healthcare services in managing her diabetes (see Image 6.31).

Image 6.31: Utility: Consultation with the healthcare professionals (Parveen)

"Whenever I feel I need to consult the doctor like when I was

having a problem in my foot I was feeling pain, so I call the

doctor ad explained that I was feeling pain in foot, so they called

me immediately about having a proper check-up and suggested

medicine and along with that guided me properly about that

what I had to do to take care of it.. You have to keep it dry and

don't let it get wet, so they provide proper help. Sometimes they

give you leaflets as well and sometimes just tell you the

information verbally (Parveen, p.77, 2256-2273).''

Participants also expressed the support provided to the people living with long-term medical conditions in the form of exemption certificates that allow them to ask for medication free of charges, as being a patient of a long-term medical condition can create economic strain. Zafar took a photograph of his exemption certificate to reflect on the material support provided in managing diabetes (see Image 6.32).

Image 6.32: Material support: exemption certificates
(Zafar)
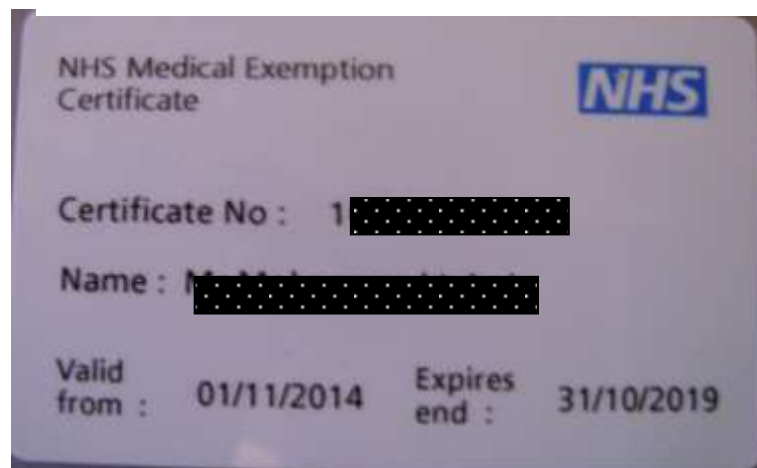
"This is very good services for the people who are on regular

medication. It can be for three to four years, and you can have

free medicine with this certificate, it helps you with financial

matters and doesn't put a strain on your pocket" (Zafar, p.91,

2708-2713).

Participants also accessed NHS services provided to combat any psychological problems. A few of the participants spoke about the psychological stresses of being diabetic and their experience of availing psychological services. They shared their experience remained less effective due to cultural and religious differences between receiver and provider of psychological services. Further language barrier was also considered a major factor in this regard. It was suggested by the participants that there should be specific psychological services for the people with diabetes according to the cultural needs of South Asians. Umer shared his experience in this way.

"I have availed psychological services for the stress and

psychological problems that I was facing while living with

diabetes. It is like people are sitting around and a topic of

discussion is going on (Positive talk), and everybody shares their

stories. These kinds of things are there, but there is need to have

proper psychological services particularly for people with

diabetes" (Umer, p.123, 3757-3771).

This account reflects the need for psychological services particularly for people with diabetes. Although participants attended the sessions provided by psychological services, they emphasised the need for more focused services, particularly for people with diabetes and to cater the need for people from the South Asian community.

6.2.2   Sub-theme two: Experiences with the healthcare professionals

There were mixed thoughts shared by the participants around their experiences with the healthcare professionals. Participants felt somehow dissatisfied in describing their experiences with the healthcare professionals. They shared their narratives about facing the stigma that the more frequent users of healthcare services being members of the South Asian community in the UK. Further religious and cultural differences for the receiver and provider of healthcare services were considered another factor in this regard. It was suggested that differences in cultural traditions around different diseases be acknowledged and this recognition should then be reflected back to the individuals according to their level of understanding through simple and plain conversation. A Participant's level of education and the information they have was considered one of the major determinants in shaping their relationship with the healthcare providers in managing health. One of the participants shared her story of self-study, not as a personal responsibility, but as a way to avoid the shame associated with the response she received from the healthcare professionals. Fatima described her thoughts about it:

> *"They (healthcare professionals) are not very helpful...... I*
> *know....when I used to go to the surgery I took leaflets from there*
> *and read them so I could be aware of things you can talk about*
> *with the doctor" (Fatima, p.22, 698-701).*

Parveen shared her story about her acknowledgement of the personal responsibility in diabetes management. She had indicted shared decision making through the process of mutual discussion with the healthcare professional. This particular female participant is running her own business and had completed her university education, which might be a possible determinant in shaping her experience with the healthcare professionals.

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"It happens that sometimes you just hear what the doctor tells

you.... and sometimes it happens.. like sometimes I used to say

that I want to do this in managing diabetes and I want to take

medicine for it. Like I used to say that I want to try this so give

me some time to look at it and I want to make it regular through

this. I want to adopt something and want to leave some things

that might helpful. The doctor always encourages you that if you

want to do something you can do it. They used to say that you

should take your time if you want to take one or two weeks you

can have it, in the end, you have to be better" (Parveen, p.70-71,

2048-2069).

Participants also shared their experience of being stigmatised by the healthcare

professionals with the opinion that South Asians were overprotective towards the health of

their children and for that reason they had more frequent visits to healthcare services. The

majority of the participants showed less awareness about the different healthcare services.

They found it daunting being told by the doctor that they should go to the pharmacy for

this problem instead of coming to the doctor. Fatima shared her experience in this regard:

"Like sometimes when you take the children to the doctor so…

like you Asian mothers are overprotective about your children if

you have got a sore throat or fever they will treat you like this...

What is this you just can have paracetamol for it, means we visit

the doctor more. So for that reason, I try to avoid visiting the

doctor, but then my mother got angry and said that you should

go to the doctor. I try to wait, and when the problem got worse

then I used to go to the doctor means they believe you that you

are ill" (Fatima, p.27, 824-839).

The attitude of the healthcare professionals towards frequent visits of the people from the South Asian community may have a long-term effect on the health of the people. They feel stigmatised and try to avoid seeking help for their medical conditions due to the negative experience with the healthcare professionals. Patient empowerment through information and trust were viewed as fundamental requirements for the ownership and successful management of health conditions. Wajeeha reflected upon this issue (see Image 6.33).

Image 6.33: Different healthcare services
(Wajeeha)

"NHS staff should also reflect upon their attitude in this

regard. They should be lenient somehow. They should

consider the circumstances and conditions of the people in

responding to them" (Wajeeha, p.55, 1623-1643).

Cultural and religious differences between the provider and the receiver of the psychological services had more profound effects, and it was proved less effective in

dealing with the depressive state of some participants, as Fatima narrates in her story of sessions with the psychologist:

> *"But she does not understand you….. Your cultural,*
>
> *religious things are totally different from her. Like she*
>
> *used to say… you should go out and make some friends..*
>
> *you should go to a club. So I can't do all these things. She*
>
> *said if you follow me you will feel better but I can't do*
>
> *that… as our culture is totally different… isn't it?"*
>
> *(Fatima, 20, 632-637).*

Communication within healthcare settings is considered a two-way process. People need to explain their condition to the healthcare professionals and from the other side healthcare professionals should consider the comprehension of the user of healthcare services. The concept of health literacy should also match the skills and capacities of the individuals and the complexity of the healthcare system as well. It emphasises the improvement of the health literacy levels of the people, and on the other side, it also stressed the simplification of the healthcare system to make it easy and accessible to people with higher and lower levels of literacy and health literacy skills. Participants also mentioned about the role of healthcare professionals in the provision of effective health services for the people. Wajeeha talked about it in her narrative.

> *"Doctors should explain their information in a simple language*
>
> *so that people with limited language abilities can also*
>
> *understand the information provided. It will also increase the*
>
> *understanding of the people as well, and the person won't feel*

hesitated about expressing his/her problems next time"

(Wajeeha, p.34, 1017-1026).

Culture emerged as an important variable in this research with the South Asian community. Participants also mentioned about some of the (South Asian) cultural remedies and treatments for diabetes. Healthcare professionals awareness about the cultural background of the particular community can be beneficial in providing tailored services to the people of that community. Saeed stressed this consideration of culture in the provision of healthcare services to the South Asian community.

"Doctors should also have some knowledge about the culture

and community of the patients, so she will better understand the

situation and circumstances of the patient and deal with him

accordingly. They know which community this person comes

from and what kind of cultural traditions and taboos are

prevalent in that community" (Saeed, p. 60, 1771-1783).

Saeed's account above also reflected the need to have some knowledge of the cultural background of the people from ethnic communities, as cultural norms and traditions have a profound effect on the behaviours and habits related to the disease and management of the condition. This can help to revise the care and treatment plan keeping in mind the barriers that particular person is facing.

6.2.3   Sub-theme three: Expressed needs and recommendations

6.2.4

This theme is concerned with the expected changes in health care settings suggested by the participants. There were plenty of suggestions and recommendations provided by the participants specific to the South Asian community's healthcare service requirements in the

UK. The majority of participants were happy with the health care received for managing diabetes. English language perceived as a barrier was a common theme across the majority of the participants' narratives; particularly that providing information and services in the native language of the participants could be more efficient and effective. People with limited or no English language ability may not understand the information provided in the English language, and on the other hand, it may be a waste of resources without outcomes. As mentioned earlier, people do not have the habit of reading leaflets, so it was suggested by the participants to provide more relevant information in person to the participant during their appointment with the healthcare professionals. Fatima shared her opinion about it:

> *"They should give more information because everybody will not*
>
> *go and pick up the information leaflets. Very rarely does*
>
> *somebody go and take them, so it is better to give more*
>
> *information because in surgery they have the information about*
>
> *what people have got and what disease so it is better to call them*
>
> *after every three months to review their condition. They can ask*
>
> *what they are eating and how they are managing their condition.*
>
> *Instead, they wait until that patient will come and tell them about*
>
> *the issues" (Fatima, p.30, 941-952).*

Participants' accounts also suggested the need for spreading information at the community level to produce a better outcome regarding motivating people to take responsibility for their care. Saeed talked about this aspect:

> *"Information needs to spread at the community level. We try to*
>
> *motivate people that have got this problem and what they can do*

to overcome this problem… you have to take control of it

yourself and improve your health" (Saeed, p.63, 1893-1900).

The analysis also suggested that participants' level of education also matters in following the instructions provided in managing their condition. It was recommended that people with limited education levels might struggle to follow the instructions provided which can be overcome by providing audio information. Participants also mentioned about the need to publicise the information within the community to increase awareness at the community level. Zafar shared his experience and raised the concern over the lack of publicity of the resources and information related to health within the community.

"Last month I had a chance to attend a meeting with people who

had a connection to the healthcare services… I had this chance

as I was involved in managing the place and other things for the

meeting. I found it really useful and that it can be accessible to

the majority of community members, but there was no publicity

about that event, so most people were not even aware that it was

happening" (Zafar, p.83, 2436-2455).

There is a need to focus on the cultural health literacy in providing health services for people from the South Asian community. Parveen shared her thoughts:

"Doctors should try to talk differently to people from a South

Asian background; they know how our diet is putting us at risk

so they need to properly guide them about how the English diet

could be putting English people at risk. They should also

properly guide people on how your cultural diet can increase the

risk of complications with diabetes and that you should try to

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have control over it. People need to be aware of what What the

high risks are for in your diet and related things… so they should

try to separate things according to the need of the patient"

(Parveen, p.69, 2015-2082).

The Participants' narratives also showed that healthcare professionals have the responsibility to provide more information and ask more questions according to the needs of the people. The participants shared the concern about sometimes forgetting things they wished to discuss with the doctor or sometimes being unaware about what they are supposed to ask healthcare professionals. As a means to overcome this situation Participants suggested asking more questions and providing more information to the patients. Abid shared his suggestions in this regard.

"Healthcare professionals should ask me more questions

according to my situation because sometimes I have planned

things that what I will discuss but I forget some things. So to

overcome these issues healthcare professionals should ask more

questions to the patient to find out more about their condition"

(Abid, p.101, 3035-3045).

Information needs to be spread across the whole community not only for people with diabetes. The use of different sources for spreading information and raising awareness was also discussed by participants. Regarding this matter, considerations should be made according to the needs of the people of that community. Zafar also suggested the use of different platforms that were considered more popular in the community, including media which should be used to raise awareness about health promotion.

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"TV channels also can be used to spread information within the

community. For that purpose, you need to have background

information about the community, such as what channel are they

watching? There are lots of TV channels that can be useful to

access for spreading information about health-related matters"

(Zafar, p.84, 2486-2494).

There was also need to consider the strengths of that particular community in promoting healthy behaviours. Religious unity can be used as a way to promote healthy behaviour of this particular community. There is already the practice of using the mosque as a channel to promote healthy behaviours in the community, but it can be used more extensively. Saleem shared his experience of using mosques as a way to promote the health of the community (see Image 6.34).

Image 6.34: Use of commonality in
promoting healthy behaviours (Saleem)

"Our GP is using the mosque very effectively in promoting

healthy behaviours in this community. Whenever there is time for

any vaccine like hepatitis or flu jabs he is effectively using this

platform to raise awareness and involvement of the people in it.

A mosque is a proper hub for the community 700-800 people

gather over there for prayer, so this is a most suitable time to

spread any message very effectively in the community" (Saleem,

p.87, 2561-2580).

There was also need to motivate people to be part of the upcoming research related to diabetes. The participants also mentioned that a cohesive attitude amongst the people could also be a positive strength in the promotion of healthy lifestyles in the community. Thoughts were also shared about the arrangement of events by the people of the community in providing help in diabetes management and in reducing the risk of getting diabetes in this higher risk group in the UK. Wajeeha highlighted the need for participation from the community members:

"Educated people of the community should motivate the people in

raising awareness and encouraging the adoption of healthy

behaviours because it is all about the development of the habits.

Once healthy behaviours are developed, then it is easy to continue

healthy behaviour further. So it all can be possible if educated

people of our community come forward and voluntarily be part of

this campaign to create healthy community" (Wajeeha, p.51, 1480-

1491).

It was also suggested through the participants' accounts that people may have information shared by the health care professionals, but they may lack the internal motivation to apply a healthy behaviour. People may go for the treatment of the diagnosed medical condition, but there was a lack of motivation to take action in preventing diseases and having a healthy life by adopting healthy lifestyle choices and behaviours. There was a need to increase the awareness to use the preventive services. The use of services to

prevent medical conditions needed to spread more vastly across the community to increase the participation of the community who were at risk of any particular disease.

6.3   Theme three: Quality of life

The life of every person with diabetes is unique, and some people can manage their condition more effectively than others. Participants shared the changes in their life after diabetes and how it had affected their life in many ways. They faced problems ranging from their health through to work life. Participants talked about the effects of diabetes on different parts of the body (foot, eyes and nails) and the reduced quality of life from living with diabetes, Umer shared his thoughts on this issue:

> *"My life completely changed after diabetes. My personal life has*
> *completely changed after diabetes. Sometimes you can manage*
> *it. When I talk to my brother he used to say 'it never happened to*
> *me it just happen to you'... But I know personally I never have*
> *any problem in my life I have worked in the army that is a hard*
> *job I have done work for continues 72 hours I never had any*
> *problem but now it is hard to even to work for three hours, so it*
> *affects me in all areas of my life" (Umer, p.130, 3991-4001).*

Nasib took a photograph of his feet to reflect on the effects of diabetes on his feet that ultimately affect his mobility (see Image 6.35, p. 272).

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Image 6.35: Effects of diabetes on the foot:
swollen feet reduced mobility (Nasib)

"I have got too much pain in my feet.... it is really hard for me to

travel. Feet can be swollen if I take a little journey. Then I do

massage with oil, and sometimes my wife does a massage that

relaxes me. I have also consulted with the doctor about it, and he

recommends special shoes to cope this problem. But we are used

to wearing our own style of shoes. I have bought the shoes, but I

am not using them because my feet do not feel comfortable in

those shoes" (Nasib, p.2, 26-38).

There were some participants who shared their experiences of psychological effects while living with diabetes. According to these participants, cognitive thoughts and thinking patterns are also an important determinant in defining the quality of life and living with diabetes. People with diabetes have a lower tolerance in the face of stressful events. Umer shared his thoughts around this:

"There are many psychological issues associated with diabetes.

Some people admit them, and some do not. I have this fear in

your mind that if I talk to somebody, others will have this

perception that he is such a big man but has got a tiny heart.

There are social pressures and fears associated with

psychological problems. In reality, all these things have

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damaging effects, and if you have got diabetes, then the speed of

this damage will increase. I will give you an example of my

father in law. He used to say that a diabetic person is like a tree

(shahtoot), that looks green outside but it is actually empty

inside and if you hit the tree your hand that will strike inside the

stem. A diabetic person is just like that; you will look healthy

and alright from the outside but inside the damage is realised

when everything collapses down"(Umer, p.122, 3714-3753).

Participants also shared their experiences of facing difficulties with food at social gatherings. A person can feel alienated as a result of avoiding food on social gatherings. The food mainly presented at social occasions is made up of a high oil and fat content. Participants shared the experiences of visiting friends and families as being problematic for people with diabetes because healthy choices were often not available. This underscored the importance of efforts to educate South Asians family members and communities about healthy eating as an important aspect of diabetes care and at a more general level as part of healthy lifestyle. Wajeeha shared her experience in this regard:

"If we talk about any special occasion… like a party, or Eid

celebration or we just have get-together then there are plenty of

things involved in it, but we mainly focus on food and do not pay

attention towards what we are eating. We don't care about the

nutritional value of food and especially for people with diabetes.

However, if they are not having options available according to

their needs that can be a problem for them" (Wajeeha, p.38, 1116-

1123).

Participants also observed that the most affected area of their life after diabetes was their work-life demands. The majority of male participants were taxi drivers and worked for long hours. They found themselves unable to manage working hours with their job conditions. Previously, they were used to working long hours with the same things going on even after they were diagnosed with diabetes, so their health was affected in a negative way. They may not have had any complication at the moment or considered their condition as being under control, but they were ignoring the long-term effects of job routine on their health and particularly on diabetes. Saeed shared his photograph of working as a taxi driver and his thoughts about it (see Image 6.36).

Image 6.36: Struggling to manage
working conditions and diabetes (Saeed)

"Sometimes you have to work for 12-14 hours or maybe 18 hours. If I am continuously working for 16 hours and sitting in the same position for a long time without any physical activity that is very bad for health and especially for diabetes.... so there is a need to have better management in my daily life that fits with diabetes. Because it is not for one day, it is a long term condition" (Saeed, p.41, 1221-1228).

Throughout the participants' stories, it was cited again and again that jobs were a hindrance to physical activity and the regular intake of medicine along with a balanced and healthy diet was needed. Saleem shared his personal experience about the devastating effects of working for long hours which not only had an effect on his health but his family relations and the future of his children in the long run. He emphasised that it depends on the nature of the job and whether you can manage it with diabetes, or not.

> *"You know driving a taxi is a very flexible job if you want to*
> *build a routine you can easily manage it.... if you have a set*
> *routine you can give time to your children, and your family*
> *environment will be pleasant as you will be able to give quality*
> *time to your children and above all these things your health will*
> *remain very good. So it is basically about your thinking and the*
> *beliefs that are set and firmed in the back of your mind"*
> *(Saleem, p.102, 3057-3071).*

The participants' accounts suggested the lack of control in managing diabetes ranged from the causation to the management of diabetes. Participants also shared their thoughts around attitudes and behaviours towards diabetes and health in general. Participants' accounts suggested a lack of attention towards health-related matters from themselves. Saeed shared his experience in this regard:

> *"We need to raise awareness within the whole community not*
> *just for diabetes. Honestly, I will tell you; we don't prioritise*
> *health until we get ill. Like if somebody has got any medical*
> *condition cholesterol or diabetes and if he can work he will*
> *continue to do so and wouldn't do anything to improve it or*

make his life better. So actually we have this attitude towards

health, and we take it for granted" (Saeed, p.49, 1428-1437).

Provision of knowledge alone may not be considered sufficient; behaviour modification strategies can also be part of a plan in bringing change within the community. Saleem, one of the active community members, shared his experience. He emphasised the need to have an inner motivation in maintaining health instead of depending and waiting for others to come and do something for you.

"In some cases, people do not know about the effect of their

actions and behaviours on their health and in some cases they

have the information, but they do not bother and intentionally

ignore it. So the most important thing within our community is to

raise awareness about the common problems of our people.

They have to realise that these things are for you... and for your

health. Healthcare professionals and NHS staff can't help the

people if they do not realise their own responsibility in

managing their health" (Saleem, p.86-87, 2550-2565).

Diabetes as a long term condition requires long-term management in all areas (i.e. medicine, exercise, diet and regular reviews with healthcare professionals). Participants' accounts also indicated the lack of motivation towards adopting organised and regular management skills needed to take control of their diabetes condition. It was also indicated through the participants' narratives that the complexity of social lives could act as a hindrance in managing their condition, mostly through a lack control regarding all these situations. Tayab shared his photograph and his thoughts and experiences in this regard (see Image 6.37, p. 277).

Image 6.37: Struggle to create balance in life
(Tayyab)

"We have this kind of environment within the community or in our homes that we people (including myself) have no time to take medicine at the proper time. If we have to meet somebody or somebody is going to Pakistan or coming from there. We have to attend any marriage, and we prefer to attend all these things and place less importance on taking medicines. Because if there is a family member or relative and if I missed meeting them they might get angry, or I will be conscious about my social image. So I will delay the medicine intake. There is too much social pressure, and we do not care about our health" (Tayyab, p. 86, 2539-2550).

Participants talked about the barriers in managing their condition. Most of them knew the need to change long-standing habits that are bad for their health but found they were unable to change these habits. The majority of participants relate these responses to their socially developed behaviours since childhood that have become their lifestyle now. Counselling and guidance in this regard can be beneficial in bringing change that results in a positive effect on the management of diabetes. People who are struggling with the effective management of diabetes can be benefitted through social support available within their families. Participants shared their views about the role of the family in managing their

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condition. They shared the supportive attitude of the families and relatives that were helping them to manage their condition in a positive way. One of the female participants diagnosed with depression, living with diabetes and who was divorced had gone through a period of emotional turmoil. Considering these circumstances she valued the emotional and material support available from her parents.

> *"I got really good support from my family, especially from my parents. If they were not here how I don't know how could have coped with these circumstances. Although at the same time I felt that I have put pressure on my parents even then their support helped me a lot to come out of this hard time in my life" (Fatima, p.22, 677-683).*

The participants account narrated that family support, particularly for the male members of the family, was very important. Nasib shared how he was getting support from his family and that it had helped him in managing to attend social gatherings while still eating a healthy diet. It showed the effect of positive support available within their families particularly for male people who do not have a direct involvement in cooking.

> *"At home my wife and daughter prepare grilled or baked food for me.... last year during Ramadhan wherever we go for* **'aftaar' parties** *my wife used to take special food for me to each place so I could have what is suitable for my health because mainly at these events things are mainly deep fried" (Nasib, p.17, 530-535).*

It has been evident through the narratives of the participants that their quality of life has been compromised after living with diabetes. They have shown a lack of control

regarding certain aspects of their life. However, with the social, emotional and material support available within their families, this has helped them with the effective management of diabetes.

6.4 Discussion

The Photovoice method revealed a number of factors that contributed to the participants' experiences of diabetes management and their health literacy needs. The use of participants' native language through the PV process considered very important to have rich data about their experiences. The data suggested that culture had a strong influence on all areas of diabetes management, specifically self-management of the condition. The first theme identified the self-management of diabetes in daily life about the lifestyle, clinical measures of diabetes management, and how health literacy at the individual level- within the context of this community, have affected the process of diabetes management. The second theme situated health literacy and the process of diabetes management in the context of healthcare settings. The final theme described the impact of diabetes on the quality of life of the participants.

The first theme titled *'Illustration of self-management of diabetes in day-to-day life'* highlighted the individual characteristics and responsibilities in the management of diabetes and the relative implication of health literacy at the individual level and within community settings. The narratives and images taken by the participants showed the cultural perspective of the South Asians community. Food and eating were mentioned as a significant part of the management of diabetes in the participants' narratives. Cultural-based cooking traditions were cited as a risk factor for better diabetes management i.e. the higher use of spices, more saturated fat content, use of traditional sweets and cooking traditions of frying and deep frying were among the few mentioned. Traditional sweets that are high in fat and sugar content are considered very popular in the South Asian community. Participants also mentioned that the use of traditional sweet increases the risk of developing diabetes. Another interesting factor around the use of sweets and the

development of diabetes was the conception of sugar use related to the development of

diabetes; *sugar* was used as a common noun to describe diabetes. It also reflected that

participants tended to focus on the sugar and food items that were sweet in nature but were

not talking about the fat and carbohydrates in food and how the use of strong spices can

also have the potential risks for diabetes. Furthermore, the concept of balanced and healthy

eating was also mentioned as a cause for concern in this community. As discussed by

Wanger et al. (2007), health literacy can foster healthy behaviours and development of the

intervention at the individual level and within the community settings which need to be

considered from the cultural perspective of this community. In this regard, strictly

culturally defined roles can also act as a barrier to bringing change. For example, being a

male member of the South Asian community means they have reduced or no involvement

in cooking. This highlights the need to involve the whole family particularly females in

providing education and information to the management of diabetes because certain aspects

of diabetes management like food have strong cultural traditions with the dominant role of

females in this area. The female narratives also supported this aspect as they had changed

their cooking patterns after becoming diabetic.

Lee et al. (2004) explain the relationship between health literacy and social support

and suggest that positive resources and support in an individual's social network can

improve their ability to acquire and act on the information needed to manage their health.

In line with the findings of the present research, the consideration of support from family

members in adopting healthy eating as part of diabetes management is important. The

participants have the knowledge and awareness about healthy diet and food as part of

diabetes care, but with the help of family support, this knowledge can be converted into

action. All these experiences shared around food and diet reflected the cultural perspective

about diabetes management and highlighted the need to link South Asian community members to the community resources to help promote healthy cooking methods.

Participants also shared their thoughts about eating habits that included late night eating, eating in large portions and less concern over the nutritional value of the food. Potential justification of these behaviours could be identified in the working pattern and the easy availability of food that can be consumed alongside managing work. It was also highlighted that the nature of jobs and employment could determine lifestyle and behaviours for these people particularly when they had a lower paid job as the economic pressure created constraints in adapting the set pattern for bringing in healthy food to their lifestyle. Conceptual models of health literacy consistently mentioned the role of socio-economic factors that define the health literacy of the individuals, Palwak (2005), considered employment and the nature of employment important in this regard. The participants' experiences thus suggested how significant these variables can be in defining healthy behaviours. This also raises a criticism in regards to the definition of health literacy that just focuses on individual skills without taking into consideration factors in the wider social environment that may have serious implications in supporting the required changes to adopt a healthy lifestyle.

Participants also talked about cultural remedies in treating diabetes that included spirituality, herbal treatment and natural South Asian food as part of treating diabetes. For example, regular use of this food ***karaila, oakra*** and leaves of the ***neem tree*** were considered effective in lowering blood glucose levels. It shows the cultural model of health and illness of South Asians that sweet cause diabetes so the bitterness of these foods can help to create the balance within the body. This also highlighted the need to consider the cultural health literacy to understand the cultural beliefs and behaviours of this community

in developing care plans and particularly considering existing conventional methods as part of the effective control of blood glucose level.

Physical activity is an important part of diabetes management, and the majority of the participants reported little or no physical activity. In previous research, there is limited data available that looks into the physical activity level in native South Asians but existing evidence suggests a lower level of regular exercise in native South Asians in comparison to other regions (Joshi et al., 2007). In existing research, the reported barriers for not doing physical exercise were working conditions, the weather conditions in the UK, and a lack of habit from not doing physical activity since childhood. Participants mainly prefer to have different ways of relaxing than being involved in leisure time activities that require physical exertion. Among the female participants, most of the mentioned reasons for not doing physical activity were family responsibilities that wouldn't allow being part of the structured physical activity which particularly affected joining a gym. There were a few exercise options that were mentioned as being acceptable, including walking and swimming, but again in the case of females, these can be restricted with some further factors due to their cultural and religious traditions. Participants mainly have the knowledge about the importance of physical activity, but this was not put into practice currently in their daily life. Achieving the aims to promote healthy behaviours as a result of improved health literacy thus suggests it should go beyond the provision of information. Nutbeam (2008) observes that people should be given help in developing the confidence to act on the knowledge that can be achieved through a more personal form of communication, and through community-based educational outreach. The focus of these interventions should not only be based on the personal skills and capacities but also consider wider social and cultural determinants.

People from the South Asian community not adhering to a Western style of doing structured exercise prefer to adopt a day to day activity as a substitute for doing exercise. Males considered their routine and worked at their job as a way of being physically active while females' household chores were mentioned as a substitute for physical activity. Another important factor in this regard is setting life priorities. In South Asian culture, personal needs come last as it can be considered selfish to focus more on personal needs such as taking part in any physical activity or exercise. This would come last as it would be considered a personal need. In the face of different roles and demands of life, an individual has to compromise on some things, and in this case, the needs related to self-care compromised.

Provision and facilitation regarding culturally acceptable ways of undertaking physical activity can be a positive way of bringing change in the lives of these people. The consideration of physical activity as a clinical recommendation is just as, important as the use of medications to improve the level of physical activity in this community. A report of Health Technology Assessment (2002) suggested that more South Asian women were willing to do exercise if prescribed by their healthcare professional. This could be a particularly affecting model to use when working with people who are at a risk of obesity or obesity-related medical conditions (Carroll, Ali & Azam, 2002). The most referenced barriers for not engaging in physical activity concerned external reasons and factors. This also highlights the need to increase and enlighten the importance of internal motivation and encourage a consistent attitude around the importance of taking part in physical activity. This can be increased through improved self-efficacy and by providing other support needed within the community to increase physical activity levels. Friis et al. (2016) also mentioned the difficulty to navigate and act upon a large number of recommendations on diet and physical activity behaviour in people with diabetes.

Present research does suggest that participants are struggling to adopt regular physical activity as part of diabetes management. Participants also shared the positive effects of the taking exercise that helped to monitor the blood glucose level of the participants. Despite the positive effects, participants found it hard to sustain exercise behaviours that acknowledge the role of improved self-efficacy which might be helpful in this regard. Previous research supports the recognition that higher self-efficacy is associated with improved health behaviours and clinical outcomes (Remmers et al., 2009; Greenfield et al., 1985; Song, 2010; Weng et al., 2010; King et al., 2010).

Studies also suggest that self-management support that includes behaviour change strategies and problem-solving skills is more likely to lead to improved self-efficacy and lifestyle modification (Bourbeau et al., 2010; Glasgow et al., 2004). Within this dimension, health literacy as an asset focuses on developing age and context specific knowledge for the individuals in combination with self-efficacy to put all this knowledge into practice and make appropriate decisions to take control of their health (Nutbeam, 2000). Furthermore, it demonstrates that health literacy is more than just being able to read the health care information and making appointments. By improving the people's access to healthcare information and building their capacity to use it effectively, health literacy is critical to empowerment (Nutbeam, 1998) that will enable them to make the necessary decisions as part of their self-management of diabetes, and in this case it is important to undertake exercise as part of diabetes management.

The fast and complex demands of living in a developed western society add some extra pressure in coping with daily challenges especially for people who belong to ethnic minorities. They also face the challenge of a continued struggle to meet the ever changing demands of modern life in western countries. Socioeconomic conditions are considered one of the major factors in adapting to the healthy lifestyles described by the participants

as well as economic pressures not allowing them to get out and spend some time exercising and investing in healthy eating as part of diabetes management. In this regard, it is important to consider the intricate link between culture, power and ethnic status to understand historical, social and political contexts in particular reference to the efforts that aim to reduce disparities in health (Estacio, 2013).

The findings from the data also show that medicine was mentioned as the most important aspect of diabetes management by the participants. It highlights the knowledge about the contribution of regular intake of medication as being effective in the management of diabetes. Squiers et al. (2012) mentioned that prior knowledge is important in developing the interventions to improve the health literacy of the individuals. Current research has shown that participants have knowledge about the nature of diabetes and its management process, including medicine intake, physical activity and healthy diet. However, the participants struggled to maintain a regular intake of the medicines and it was suggested by one of the participants that captured some of the images that the complications of diabetes can be placed on the packaging of the medication to act as a reminder to commit to the regular intake of medicines that will reduce the risk of complications in later life.

Participants also shared the cultural remedies that can be used to treat diabetes. According to the experiences of the participants, these cultural remedies are considered effective in managing diabetes and highlight the need to raise awareness in healthcare professionals about the unique cultural perspective that can also be considered in discussing the management plan with the individuals. The cultural remedies in any community that are effective can be part of the management plan. In some cases, the participants seek alternative treatment for their condition applying a cultural frame of mind that there will be some magic cure available to their condition that is beyond the notion of

modern science. Particularly in diabetes, the discontinuation of on-going medical treatment results in the poor diabetes control and other health-related problems. Friis et al. (2016) thus suggest that diabetic patients may find it hard to adhere to the recommended treatment guidelines and face difficulty in understanding health-related information that highlight the provision of facilities that enable individuals to act upon their management plan.

Individuals who struggle to act upon the prescribed medications and showed less involvement in their medication plan demonstrates that the information and services provided may not be according to the requirements of the people (e.g. insulin, anti-depressant therapy) (Parker & Swain, 2010; Bauer et al., 2013). From the perspective of ethnic minorities, it has become more crucial to check the suitability of the services and information is according to the needs of the people to enable and empower them to take good control of their condition. In the process of improving health literacy, Estacio and Comings (2013) also mentioned about the need to consider the relevance of social context in determining the engagement and participation of individuals in health care. Socioeconomic, political and cultural factors could have an impact on people's ability and willingness to participate in health-related programs.

Blood glucose monitoring was also another important area of diabetes management. This is the area that needs to reflect the skills and motivation needed to increase the regular monitoring of blood glucose levels. Participants' accounts reflected this recognition that it is the responsibility of the healthcare professionals to check the blood glucose level for them. There is a need to create awareness about the importance to learn and monitor blood glucose level as part of self-management too. One of the participants, who check their blood glucose level on a regular basis, gave himself reassurance about the condition of his health, and regular monitoring helped him to gain a sense of control in his life. Another interesting finding was about applying subjective

assessment to monitor blood glucose levels. Although living with chronic medical conditions for a long time can develop an experiential learning experience, this cannot be a substitute for more objective measures of blood glucose monitoring.

Previous research has demonstrated an association between an adequate level of health literacy and glycaemic control (Schillinger et al., 2002). Another research example recorded poorer glycaemic control in South Asians along with poorer knowledge of diabetes (Hawthorne & Tomlinson, 1999). Brega et al. (2012) found a positive association between health literacy and glycaemic control in a study conducted with American Indians and Alaskan Natives in the United States. The numeracy component of health literacy is reported as being important in glycaemic control (Cavangaugh et al., 2008; Marden et al., 2012) and it was also significant in explaining racial disparity in glycaemic control (Osborn et al., 2009). Current research has a demonstrated lack of blood glucose monitoring among participants which highlights this area should be considered. In the provision of a care plan and to look for the ways how individuals can be involved with this important part of diabetes self-management.

NICE (2015) guidelines recommend regular monitoring of blood glucose levels for adults with type 2 diabetes in the case of those taking oral medication because it can increase their risk of hypoglycaemia while driving. The majority of male participants were taxi drivers; this highlights how important it is for them to monitor their blood glucose level to keep their diabetes under control while keeping in mind the nature of their job as part of effectively managing diabetes. Some of the Participants also mentioned that they had their blood glucose monitored by their family members which implied that instead of referring it to the sole responsibility of individuals, applying their individual health literacy skills, the community resources of getting support from family should be considered. Edwards, Fiona, Davies, and Adrian (2013) also acknowledged the concept of distributed

health literacy and emphasised that health literacy skills can be dispersed amongst individuals' social networks including family, friends, and community members. It showed how individuals drew on the health literacy abilities, skills and practices of others as a resource to help them seek, understand and use health information to manage their condition.

Within the theme of *illustration of self-management of diabetes in day-to-day life*, participants' narratives also described the issues around personal skills and capacities that link with health literacy and diabetes management. Participants mentioned about the lack of readability of written information such as that provided in the form of leaflets that came with the medications or product labels at the marketplaces when they look for the nutritious value of the food. One of the reasons of not utilising written information is that the information is provided in the English language, but in this regard, they also mentioned about how family members who have good English language abilities help them to read the information. The English language was considered a major barrier in the effective utilisation of healthcare services for the people whose native language is not English. It acts as a barrier at different levels and in different ways. Firstly, it acts as a barrier when accessing the right healthcare information and services, secondly, during communication with the health care providers (difficulty in expressing and explaining the problem), and finally, preventing the utilisation of health care information written in English language (printed, digital).

Participants shared their experiences of feeling unable to effectively express their symptoms due to a limited knowledge of scientific vocabulary used in clinical settings. Schillinger et al. (2004) suggested that these oral communication problems can be handled by the use of simple and plain language according to the need of the individual, particularly in the technical and explanatory domains of patient-provider interaction. The

limited use of professional interpreters, and dependence on family members who were not proficient in the English language either put minority patients and carers in a disadvantaged position. In earlier research, Garish (2001), also mentioned that in some cases healthcare professionals were also dissatisfied with the relatives being used as interpreters when they had limited English proficiency or limited knowledge of medical concepts because this could lead to a misunderstanding or inaccurate interpretation of symptoms. Healthcare professionals should keep in mind the level of English language and literacy level of the individuals so that communication can be modified according to the needs of the individuals by using simple and plain language.

The majority of the leaflets presented in healthcare settings are written in the English language. This can act as a barrier in picking out and reading the health information in the written form. Participants suggested having information in their native language which might increase the use of written health information. However, the participants also highlighted the lack of readability in people from the South Asian community on health information leaflets, product labels in the supermarket, and the information leaflets provided with the medication. On the one hand, it highlights the need to promote the habit of participants reading written health information, while on the other hand it also highlights the lack of resources shared among healthcare organisations that aim to focus on some health problems. *Diabetes UK* has translated leaflets in all the main languages of ethnic minorities in the UK, but there is a need to share it with the people in primary care settings to increase the utilisation of the already existed resources (Diabetes UK, 2017).

The second theme, titled, ***'NHS access and utility in diabetes management'*** drew emphasis on the factors within the healthcare settings that can have an effect on the diabetes management in this community along with the highlighted health literacy needs.

Participants recognised the value of NHS services in their diabetes management, and they were satisfied with the service provision. Primary care services were mentioned as being easy to access and as providing the required services according to the needs of the participants. Fewer thoughts were shared around the use of different services available as part of diabetes management. Although educational interventions were considered important in improving the self-management of diabetes, none of the participants shared their experience of attending educational courses as part of diabetes management. There is a specific program developed for people belonging to the South Asian community, but only one participant mentioned it or its referral through healthcare professionals.

Educational programs specific to people with diabetes can be helpful in many ways. Lifestyle changes as part of diabetes management can put extra stress on individuals and particularly people belonging to ethnic minorities who already face the stresses of socio-cultural differences from the dominant culture in Western countries. Although a few of the participants shared their experiences of using psychological services as part of the diabetes care, there was great dissatisfaction about positive outcomes. Psychological services were provided in the English language, and the cultural and religious differences between the receiver and provider of these services made it less effective for the participants who used these services.

A Provider's lack of cultural understanding may be a barrier to improving access and in providing effective communication. In medical consultations, perceptions of physicians as the expert and authority figure, expecting compliance, makes some South Asian patients feel misunderstood. The use of an interpreter is recommended to improve communication along with the need to adopt culturally sensitive services (Wilson eta l., 2012). The ethical concern of power between health care providers and receivers can make the patients feel oppressed, and this can be more problematic for the people who speak

different languages from the healthcare professionals (Erlen, 2004). This highlighted the need to consider the factors within the healthcare settings such as communication between healthcare professionals and patients and their need for more efficiency. The individuals' health literacy skills should not be solely to blame, and this suggests the need to reflect on the capacities of health care providers too. To have participation in health care, people need to have the ability to ask questions ad challenge or seek alternative information. In this regard, Estacio and Comings (2013) draw attention to the social position that enables the individual to engage in such activities. They further acknowledged that initiatives to improve health literacy without consideration of broader sociocultural context might not be sufficient.

The discussions also highlighted that with the participants that there was also need to improve digital health literacy as a consumer of health services in the healthcare system in a developed country. It was suggested by one of the participants that an online option should be available for booking an appointment to reduce the stress of booking in the morning. It also demonstrated that people were not aware of the existing services within the healthcare services that can already be utilised according to their needs. Health literacy can also be conceptualised as a functional miss-match of the skills of the individual and the demands placed on the individual by the health care system and its providers (Castro et al., 2007) that can act as a barrier to accessing and utilising the healthcare services to maintain and improve health. According to the findings of the present research, less publicity of the pre-existing resources has been indicated as a concern by the participants.

In the theme, *NHS access and utility in diabetes management*, experiences regarding communication with the healthcare providers produced mixed thoughts from the participants. These experiences are primarily influenced by the level of education of the participants. The participants shared their thoughts about negative experiences with the

health care professionals as people from the South Asian community were considered more frequent users of the healthcare services. It reflected the lack of utilisation of the resources that aimed to enhance and improve self-care and self-management of health resources that were already available in the written form or online. This highlighted the need to signpost for the people to utilise the health related information available via different sources. It was also identified that participants mainly found face to face interaction with the healthcare providers as the effective opportunity to gain health-related information. This face to face interaction can be considered as an opportunity to provide the information about locating and accessing already available resources in the community. In the health literacy, constructive communication is described as how thoughts, messages and information are exchanged. In this perspective essential communication skills included reading with understanding, conveying ideas in writing, speaking so others can understand, listening actively and observing critically. Research in past has demonstrated that a lack of effective communication will result in errors, poor quality, and a potential risk to the patients' safety (Schyve, 2007). According to Berrett (2006), improved patient-clinician communication can improve a patient's understanding of the disease, improve understanding of the treatment plans, increased understanding about medication adherence and intake and increase patient motivation and empowerment to make the needed behavioural changes. This raised concerns over the skills and capabilities of the healthcare professionals to effectively communication with the patients. It can be challenging for the health care professionals within the healthcare system as well because they are always pushed to see as many patients as possible during one day.

Furthermore, in the context of ***NHS access and utility in diabetes management***, discussion is dominated by the expectations of the participants within the UK's NHS services. It was observed that healthcare professional should consider the cultural

background of the person as this might have a different effect on the perception of any disease and its management from a particular cultural context. The patients' cultural, experiential knowledge can also be fruitful in formulating the management plan in that specific community. It was also suggested that more information should be given to the individual first hand and in any form that meets the needs of that person, according to their requirements. Within the context of health literacy, the *cultural literacy* is important. Cultural health literacy is the recognition of collective cultural beliefs, customs, and social identity used to interpret and act on health care information and its accommodation in the provision of healthcare services (Zarcadoolas et al., 2005). It also reinforces the significance of the context in the health literacy construct that cannot be understood in isolation. It emphasised that health literacy should be addressed from a wider perspective on how an individual functions within society, and how they interact with health care providers in health systems because one individual may be health literate in one society or context but not in another (IOM, 2004; Hill, 2007; & Willimas et al., 1995).

The final theme, *'quality of life'* considered the issues surrounded by the effects of diabetes on the quality of life of the participants. Discussion with the participants revealed how diabetes had an impact on all areas of their lives, including social life, physical health, eating patterns and emotional well-being. In general, most studies reported that quality of life among people with diabetes is worse than the quality of life in the general population (Rubin & Peyrot, 1999) and there is substantial research evidence available about the impact of diabetes on quality of life (Jahanlou & Karami, 2009). However, is little evidence available regarding the level of health literacy connected to the quality of life with diabetes (Bailey et al., 2014) especially in minority ethnic communities in the UK.

Participants shared their struggle with food being presented at social gatherings that they could not eat and how it difficult for the people with diabetes to stick with to a healthy

eating routine. This showed how diabetes could have effects on a person's social life. Peer pressure in social gatherings and when visiting friends and family can be problematic for people with diabetes as insistence on eating the food presented is viewed as a sign of warm hospitality and refusing food can be considered impolite or rude. It was also revealed in previous research that traditional food is considered a source of strength and that people with diabetes want to eat it because of worry they will potentially be alienated from the community (Hanif & Karamat, 2009). The demands of social lives and gaining positive social approval are considered more important than the timely intake of medicines. A few of the participants talked about the psychological effects of being diabetic. According to one participant, every person with diabetes has psychological stress, but the difference was whether they admitted it or not. It raised the issue of being stigmatised if a person admits psychological problems. Males in the South Asian community are considered to be strong and to have psychological stresses means you are not brave enough. This highlighted the dominance of cultural beliefs over psychological stresses and indicated the mental health literacy level of people belonging to this community. Furthermore, this attitude can also limit the patients to access the relevant services to tackle the stress and psychological consequences of being diabetic. This increases the likelihood that an individual will suffer in silence.

Work life balance had huge implications in diabetes management and was discussed in regards to physical activity, eating patterns, and regular intake of medication. Participants faced struggles when acting upon the advice of the healthcare professionals regarding eating in small portions and frequently due to their work routine. The participants also mentioned that diabetes had weakened their body and it is now impossible to work as hard as they used to do before diabetes. Long working hours act as an obstacle in the effective management of diabetes. The majority of male participant recorded their

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occupation as taxi driver which requires no physical exertion during their working hours. It was also described as being an uncertain job because every time they have a new customer, interactions with that person is either positive or negative, which has an effect on their mood.

The majority of participants mentioned socio-economic factors as being major determinants that keep them pushing forward to do more work for longer hours. These thoughts shared by the participants reflected the wider socio-economic inequalities in ethnic minorities. There are inequalities in ethnic minorities in healthcare and to blame communication difficulties and cultural practices are an oversimplification of the issue. Rather it is part of wider inequalities ranging from poverty, housing and education (Hathorne, 1994). In this regard, health education to promote health literacy is not about developing personal skills to change lifestyles and develop compliance to disease management strategies. It should also focus on raising awareness about the social determinants of health and how they can be modified (Nutbeam, 2008). This approach is also in line with the recent definition provided by WHO (2015) "the consideration of individual capacities along with community resources" in defining a health literacy construct. Less suitability of the educational campaigns for health promotion and disease prevention according to the needs of the people may prove less effective. In this case, their decision related to the use of health services mainly influenced by their personal experiences rather than up-to-date health education advice (von Wagner et al., 2009).

Participants also narrated that they have a lack of control over circumstances while living with diabetes. Participants have a fatalistic attitude towards health and consider themselves out of control. Health literacy is also related to perceived control over health and self-efficacy to participate in the health-care process directly as well as indirectly. An unrealistic optimism towards complications associated with diabetes was also a common

factor, although support from friends and families help patients to gain that control back. Health literacy is fundamental to patient engagement and empowerment. If individuals do not have the capacity to obtain, process or understand basic health information, then they will not be able to look after themselves effectively or make appropriate health decisions (Coulter & Ellins, 2006).

Efforts to improve peoples' health literacy will enable them to modify their behaviours which might be helpful in reducing the complications associated with diabetes in later life. However, adherence to treatment and self-management alone are not sufficient (Glasgow & Eakin, 1996). Barlow et al. (2002) note that it is important to have effective education for diabetics as there was fourfold increased risk of complications among patients who had not received outpatient education in comparison to those who had. Existing and previous research evidence thus suggests that to improve health literacy through educational interventions will enhance the self-management of people with diabetes.

All the aspects mentioned above highlight the need to improve health literacy as discussed by Nutbeam, on three levels. Improved functional health literacy will increase the knowledge and use of health care services for prevention, immunisation and provide support in the self-management of diabetes. Improved interactive health literacy will inculcate personal skills in a supportive environment that will improve the capacity to utilise healthcare information independently with improved motivation and self-confidence. At the critical level improved health literacy will build the capacity of individuals and in the communities to act on the social and economic determinants of health and enhance community empowerment. These different levels of health literacy show the skills that help individuals to have greater autonomy and personal empowerment in making decisions and engaging in social action within the wider social environment to

address the determinants of health (Nutbeam, 2000). The findings of this research support the consideration of health literacy as an asset, as it goes beyond the narrow scope of health literacy as a risk approach.

6.5   Conclusion

Photovoice as a method used with South Asians has demonstrated the cultural aspect of diabetes management. It has also helped to situate health literacy needs within their cultural perspective and in the context of diabetes management. Participants' narratives and photographs have demonstrated that individual skills and capacities can have an important role in managing the different aspects of diabetes care. Lifestyle changes as part of diabetes management proved to be the area where participants struggled, and certain cultural norms and tradition were mentioned as both a facilitator and barrier in effective diabetes management. Access and use of the healthcare services as part of diabetes care has been discussed to a satisfactory level. The barriers have been recognised by the participants, particularly English language as a communication barrier and as a barrier to the navigation of different health care services according to the needs of the person. It has also been mentioned that diabetes has a negative impact on the quality of life of participants. Despite the difficulties in managing diabetes, participants were availing social support from their immediate social network that helped them to cope with the aspects where they lack the skills and capacities required. Furthermore, participants referred to the particular needs of their community that should also be considered in providing person-centred care for people belonging to the South Asian community in the UK. The expressed needs can be considered in delivering care plans to the people of this ethnic community, and further cost and clinical effectiveness can be evaluated in future research projects.

7 Final discussion

The motivation driving this thesis was to examine health literacy among South Asians in the UK and to improve understanding about their health literacy needs, in particular reference to diabetes management. This thesis explored the following aims.

- To examine the health literacy level of the South Asian community in the UK, and its associated social and demographic characteristics.
- To explore the participants' daily management of diabetes and their health literacy needs through the participants-led approach to gain an understanding of their unique cultural perspective.
- To identify research-based recommendations for health literacy strategy, based on the findings of this thesis through a mixed methods approach.

Rather than looking at *'health literacy as a risk'* as a dominant approach in previous research around health literacy, the aim was to take an '***asset approach'*** to explore health literacy and diabetes management of South Asians in the UK. The aims stated above led specifically to examining health literacy levels in this community (Chapter 5). Further situate the exploration of health literacy needs within their cultural perspective and diabetes management (Chapter 6). By taking an asset approach of health literacy, along with public health resources on local actions to improve health literacy and reduce health disparities to explore the research aims, a survey was conducted along with a participatory led qualitative method 'Photovoice' to explore the cultural and individual perspective of the participants. This chapter discusses the main research aims by using the findings from both studies with strengths and limitations of this study. Future research directions are also present followed by a conclusion of this thesis.

7.1 Explore and examine health literacy level of the South Asian community in the UK.

Study one, examined and assessed health literacy levels of South Asians. The results indicated that the majority of participants (61%) have limited functional health literacy. Findings also suggest that people with certain characteristics, such as old age, females, low socioeconomic status, and people with limited or no formal education, are at a higher risk of inadequate health literacy. South Asian ethnicity is also one marker for different health literacy levels among participants, and people from Indian origin have higher health literacy levels as compared to Pakistani and Bangladeshi participants. This suggests that it is important to recognise the diversity of the South Asian community when designing interventions and should be appropriate to the needs of each community. The research findings also support the necessity of developing a wider approach to address health literacy as an empowerment tool to improve individual health and community well-being. Interventions to improve the individual's skills and capacities without considering the social and demographic factors might not be an appropriate approach to improve health literacy. The findings also suggest that improved health literacy can have implications for better health outcomes and quality of life. Self-efficacy can be another relevant determinant of self-management behaviours among the population with limited health literacy skills and capacities. In practice, improvements in health literacy and self-efficacy can have better outcomes for health and an improved quality for life of individuals and communities with reduced health inequalities.

7.2   Explore the participant's daily management of diabetes and their health literacy needs within their cultural perspective.

Study two, explored the daily management of diabetes and health literacy needs of South Asians in the UK. The findings from study two reinforce the quantitative results from study one. Participants' images and narratives mentioned the lack of readability; that they did not read health care information leaflets; limited reading habits for food product labels; and a minimum calories calculation in eating food. This reflected the basic functional skills that are needed to read and comprehend the written information and make decisions accordingly. In the case of diabetics, they have to monitor blood glucose, healthy eating, calories calculation and close monitoring of blood glucose, thus suggest a serious concern as mentioned by the participants in this project. In previous research, it has been demonstrated that inadequate health literacy is independently associated with poor glycaemic control and higher rates of complications of type 2 diabetes (Schillinger et al, 2002., Powell, Hill, & Clancy, 2007., Williams et al, 1998). Nutbeam (2000) described functional health literacy as a basic level in defining health literacy capacities to function in health care settings and in the society to fully utilise the health care information and services in a journey to maintain good health. However it is also important to consider that health literacy is not simply a set of functional capabilities. It comprises a set of skills of individuals and community resources that enable individuals to participate fully in society, and to exert a higher degree of control over everyday events.

It had been demonstrated from study two that, despite the limited functional health literacy, participants are able to manage their diabetes and use social support in their families, the distributed resources and health literacy skills of their family members to overcome their personal limited capacities. This has shown that community resources can

be used to improve the health literacy of communities.

The findings also suggest, that within particular reference to diabetes management certain dimensions of health literacy are important to consider. There is a need to have implications for functional health literacy, food health literacy, digital health literacy, and scientific health literacy to improve adherence to medication, utility of health care services and self-care demands in this community. The findings also imply that in order to improve self-efficacy a supportive environment is needed to overcome the barriers not to engaging in the physical activity and to develop healthy eating habits as part of diabetes care. The findings also suggest consideration of cultural norms and traditions are important in providing care to the people belonging to ethnic communities. Every community can have assets that can be utilised to support self-management. The identification of the cultural factors that act as barriers can be minimised through a tailored approach of care for the members of that community. The findings also suggest there is a need to improve the utility of the health care resources, and information available in written form and through online resources for self-management and self-care. People from the same community can work as mentors to tap the community resources and to motivate people to critically evaluate their issues through looking at problems and what they can do to improve their health conditions and improve their quality of life.

7.3 **To identify research based recommendations for health literacy strategy, based on the findings of this thesis through a mixed methods approach.**

A number of policy initiatives in the UK have been put forward to reduce health inequalities through improved health literacy of the people who are at risk of limited health literacy skills. Brainard, Loke and Salter (2014), mentioned that health literacy interventions in mainland Europe had potentially under-target disadvantaged ethnic

minority groups. People from ethnic communities are generally vaguely represented in health literacy research. Findings, from this research, provide evidence about the health literacy levels of one ethnic minority community in the UK and support the argument that interventions are needed to improve the health literacy of people belonging to ethnic communities. In this section, the strategies to improve health literacy in this community are presented, with, the support of findings from both studies.

The following health literacy skills and capacities can be improved in diabetes management considering South Asian cultural perspective in this regard:

Functional health literacy can be improved through communication of factual information on health risks. Limited English language ability was considered as a barrier in utility of the information sources. Public Health England (2015) stressed the need to design and distribute print, audio-visuals and social media content that is easy to understand and act upon. While in this regard the information in the native language of the ethnic minorities can increase the comprehension and utility of the written material. As discussed earlier, Diabetes UK has translated information in all the ethnic languages of the UK population that need to be considered and distributed at the primary care settings and within the community. Another way to improve the comprehension of information, is the provision of audio/video information to the people with limited English language abilities. In particular reference to diabetes participants shared their struggle of regular intake of medications. The one possible way to improve the medicine adherence is to share the consequences of irregular intake of medicine. Use of pictures of the complication of the diabetes on the medications can act as a reminder to develop an insight towards the long term complications and the medication can be taken with more care to reduce later life complications associated with diabetes.

Food health literacy was mentioned as an important aspect among people from South Asian community members living with diabetes as they have strong cultural norms and traditions about food. According to the findings of this research, food health literacy can be defined as their knowledge about diet as part of diabetes care and their particular diet pattern and eating behaviours as a risk or benefit to diabetes care.

This can expand cultural perspective in defining health literacy concept within asset approach about consideration of the ability to make food choices and utilise community and personal resources in making healthy food choices and cooking patterns.

Scientific health literacy also has the potential to improve self-management of chronic conditions. According to the findings from this research, knowledge about diabetes, the importance of self-management behaviours and integration of the community members in research activities needs to be developed in the South Asian community.

Cultural health literacy is another important dimension of health literacy. That it's important to consider an understanding the beliefs related to health and disease in particular reference to ethnic communities. All the participants in study two migrated from a developing country into UK's developed and modern healthcare system.

They grew up in a "doctor-knows-best" milieu and hence the participants in this research mentioned face to face interaction with the healthcare professionals as a way of getting information and advice for managing health conditions. Consideration of their cultural background and care plan accordingly can bring more effective changes in self-management behaviours of people living with chronic conditions.

Digital health literacy is another important aspect to improve the self-management of diabetes as consumer of modern healthcare system.

In this regard, the already NHS-England digital strategy can be utilised with the people from the South Asian community. To increase their capacity and confidence in using online resources available to manage diabetes. This skill building approach can reduce the burden from offline healthcare resources and can enable individuals to utilise online information and resources to maintain and promote health.

The majority of the definitions of health literacy focus on the individual's skills and capabilities to access and utilise health information apart from the WHO (2015) definition that considers individual and community resources as part of definition of health literacy. Now it has been widely accepted in asset approach of health literacy that apart from the individual capabilities and capacities, the resources available in the individual and its social network can enable a person to be heath literate. In this regard the term of ***distributed health literacy*** was first introduced by the Edward, Wood, Davies and Edwards (2013). They adopted the term of distributed health literacy from Wagner et al's (1986) term of distributed literacy that describes the scenario, where several individuals possess different aspects of literacy and by combining their efforts they can be more fully literate. Health literacy as an asset that is disseminated from one person to another or through the group of people and the people who share these health literacy skills called mediators. This concept also extended through this research, participants having limited functional health literacy but with the support available from their social network they are able to manage their diabetes. For example participants utilised the English language ability of their immediate family network in reading information, monitoring blood glucose level and communicating with healthcare professionals. Some participants mentioned adaptation of healthy eating after diabetes as they had family

support available from the females in their families. Findings from both studies indicated presence of social capital that highlighted the more efficient implication of distributed health literacy with this particular community who have strong social and community network and cohesiveness.

Consideration of assets available in the social network and community settings can be utilised to develop health literacy as an asset in communities. People from the South Asian community can work as mentors to raise awareness about risks and management of diabetes in their community. This idea has been previously utilised in a project with South Asian men in the UK and feedback from the participants about the mentorship program was generally positive. It helped to improve their ability to understand health information; communication with the healthcare professionals; use of health services effectively; improved their knowledge of diabetes (Estacio et al, 2012). The suggestion was apparent both in this research and previous research conducted by Estacio and colleagues, and demonstrate that peer-mentoring can be one of the strategies to improve health literacy of people belonging to ethnic minority groups. This will reduce the health inequalities, as people from this community are at higher risk of developing diabetes.

Wider social determinants of health literacy have been discussed in Chapter 2 and consolidate that health literacy is associated with the social determinants of health. This has been supported with findings from present studies, that health literacy is associated with the age, gender, education, ethnicity and income. It has also been mentioned in the Public Health England (2015) initiative to improve health literacy through a lifelong strategy by improving condition where people live, work and grow up. Improving social conditions can be helpful to improve health literacy of people who are at a disadvantage of limited health literacy. Older adults may have inadequate health literacy and in that

context, the notion of adult education and lifelong learning can be utilised to develop health literacy skills in people who are aged 60+.

Health literacy is described as an asset to be developed, and seen as an outcome of health education and communication (Nutbeam, 2000). In this project, health literacy is considered as an asset. Thus the focus was not on inadequate health literacy but the development of health literacy over time for people living with long term medical conditions (Diabetes) and considering the cultural context of the participants. NICE (2009) has recommended a structured education program to adults with type 2 diabetes and/or their family members or carers (as appropriate) at and around the time of their diagnosis with annual reinforcement and reviews. The structured education programs should be according to the cultural, linguistic, cognitive and literacy needs of local communities. Despite specific structured education program of diabetes for South Asians, participants in this project did not attend structured education sessions.

In the light of the findings of this research, there is an increased need to utilise already developed educational interventions to improve self-management capacities of the people of this community. According to the findings of the present research, female members of the community need to learn more about healthy cooking methods as an important part of diabetes management. Male participants also reported the support of females in the family that help them to have healthy eating as part of diabetes care. However, a need was raised to increase the awareness in female family members (As cooking is mainly the responsibility of females in South Asian culture) about healthy eating and cooking as part of prevention and management of diabetes.

In conclusion, this thesis has highlighted the importance of functional, food and scientific health literacy in diabetes management among South Asians. In order to support

the individuals with diabetes, health care professionals and patient educators should help them to develop theses skills and carry out a regular assessment to monitor how they incorporate this into the process of their care. It has also highlighted that improving health literacy at the individual level cannot be sufficient and there is need to consider the system based factors that can be changed and improved to have easy access, utility of the healthcare information and services to people belonged to all health literacy levels. However, as indicated though the findings of present research, despite the limited functional health literacy skills, participants are using the resources in their immediate social network to cope with the demands of self-management of diabetes with an expansion of knowledge from cultural and distributed health literacy. Possibilities and implications are there to improve health literacy at individual levels and at the community level too. This effort to consider the asset approach to improve health literacy, can fulfil the agenda to reduce health inequalities through an improved health literacy of the ethnic minorities in the UK.

7.4   Strengths

This study has used a mixed methods approach to critically examine and explore health literacy, so the limitation of one method can be compensated through the other. Measurement of health literacy has been criticised for focusing too much on functional health literacy rather than the wider context of health literacy. Further, more individual screening methods largely ignore relevant influences on health literacy such as culture, language and societal norms. In this mixed methods research, an effort was put forward to use quantitative methods for individual assessments of health literacy, along with a qualitative approach to assess the influence of wider social and cultural aspects on health literacy and experience of diabetes management.

Estacio and Comings (2013) considered participatory research, as one way to engage community members in understanding and developing competencies in health literacy. In the present research, an effort was put forward to use PV as a participatory approach to understand the needs of this particular community about diabetes management and health literacy needs.

The researcher used the native language of the participants to minimise the language barrier and improve the engagement process throughout the research process. The use of the native language of the participants had added benefits at different stages of this research. It helped to recruit the participants, engagement in data collection (especially PV) and helped the participants to be more expressive in sharing their thoughts and experiences. The positionality of the researcher with the same ethnic identity and speaking similar language played a significant role in bringing out the experiences of the participants.

This study includes the participants who were living with diabetes for a long time, along with some who were recently diagnosed with diabetes. Participants in study two all belong to one ethnicity (Pakistani) and have shown a rich cultural description of one particular South Asian community, as study one suggests a variation of different health literacy levels with these sub-groups of South Asians.

This study is different from previous studies in the field of health literacy that focus more on health literacy as a risk. This study has explored health literacy as an asset and how people with different health literacy skills can improve their skills and capacity by utilising their support network.

7.5   Limitations

In this research, NVS-UK was used to assess the functional health literacy level of participants. Thus, people, who cannot read English, were excluded from the administration process. This is a limitation of health literacy measures in general. Technically it is measuring functional health literacy, but it is also testing the understanding of English. Although it is important in the UK context, however, health literacy is not just about the language and functional abilities.

All the participants in the qualitative study (Photovoice) were first generation immigrants would suggests their strong connection to the culture and association with their native countries, extended family structures, and language issues.

In study two, photovoice was used to explore how health literacy was constructed within South Asian's cultural context and in relation to diabetes. In PV, there was no action included to showcase the findings of present research and to reach policy makers/relevant stakeholders about the assets available in the community that can be utilised to improve health literacy and diabetes management in this community. To reach the policy makers, and to showcase the findings to the wider relevant stakeholders and communities, it is an important key component of PV, but in this research this aspect is not covered due to time constraints during this PhD.

7.6   Future research recommendations

My research has demonstrated that health literacy is not just a question of individual functional health literacy capacities but also involve resources in the community which is in line with the WHO (2015) definition of health literacy. Individual resources are just one source, but there are other resources that people can use too. NVS-UK as a measure

of functional health literacy could not capture these levels of health literacy. The future recommendations could be to develop other ways of exploring and measuring a community approach to health literacy. Future research is needed to develop the measures to assess the level of health literacy within a person's social network.

One way of developing this research would be to consider health literacy among members of the South Asian community, who were born here and have adequate English language abilities. This can address the question of relative contribution of English language ability in defining level of health literacy (as mentioned concern in using NVS-UK for assessing functional health literacy).

People from other South Asian communities, can be included in future participatory research to explore their cultural perspective and its contribution in understanding their needs of health literacy in relation to diabetes management.

It has been indicated, that people are benefitting from the distributed resources within their social network. This has appeared as an important finding from the present research. However, it did not say anything about the quality of information and support of these resources (i.e. health literacy skills of families and friends). People, who are providing within the wider community, may also have limited health literacy and information shared about the management of diabetes may not necessarily be appropriate for improving quality of life. The quality of social support as a mediator in improving health literacy of the individuals and communities should be explored further.

As discussed earlier in limitations section, that in the PV exercise, there was no action included that could be a future action to showcase the findings of present research and to reach policy makers/relevant stakeholders about the assets available in the community that can be utilised to improve health literacy and diabetes management in this community. Findings from PV can be passed on to the organisations and other

groups, who might want to take the recommendations on board.

7.7   Conclusion

In conclusion, it is appropriate to adopt an asset approach to improve the health literacy of people to improve their health outcomes. Health literacy as a risk approach has limited outcomes. The aims of this thesis were to examine and expand health literacy and diabetes management within the cultural perspective of the South Asian communities in the UK. The role of the researcher having same ethnic status and conducting research by using native language of the participants was advantageous that provide a rich cultural perspective of the participants within this perspective. It has been described through findings of both phases studies, despite the evidence of limited functional health literacy, the participants can rely on the resources in their community that can be helpful to compensate their limitations. This has been highlighted through the findings of this thesis, that there has been a need to go beyond the individualistic intervention strategies to improve health literacy and reduce health disparities. The consideration of health literacy within any particular community's cultural perspective can have the potential to maximise the assets of that community. In increasing such a level of awareness and contributing towards the evidence of health literacy as an asset approach, made it possible to use the distributed resources of the social networks. This can be one strategy to improve health literacy that can reduce the health related disparities in the ethnic communities. The findings of this research have identified a number of interventions that can be utilised to improve health literacy in the South Asian community. Further implementation and evaluation of these strategies are considered important for future research and practice.

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Appendices

Keele University

RESEARCH AND ENTERPRISE SERVICES

23rd July 2013

Bushra Bibi
DH1.23
Dorothy Hodgkin Building
Keele University

Dear Bushra,

Re: 'Health Literacy and Diabetes Management among South Asians in United Kingdom'

Thank you for submitting your revised application for review.

I am pleased to inform you that your application has been approved by the Ethics Review Panel. We would also like to thank you for your full response, and we wish you every success with your project. While we understand you have a system in place for interviews it may be helpful to check out fully Keele's Lone Worker Policy:
http://www.keele.ac.uk/researchsupport/researchgovernance/loneworkerguidance/

The following documents have been reviewed and approved by the panel as follows:

Document	Version	Date
Application Form	2	12 July 2013
Summary of Proposal	2	12 July 2013
Information Sheets	2	12 July 2013
Consent Forms	2	12 July 2013
Questionnaire	2	12 July 2013
Poster	2	12 July 2013

If the fieldwork goes beyond the date stated in your application, you must notify the Ethical Review Panel via the ERP administrator at uso.erps@keele.ac.uk stating ERP1 in the subject line of the e-mail.

If there are any other amendments to your study you must submit an 'application to amend study' form to the ERP administrator stating ERP1 in the subject line of the e-mail. This form is available via http://www.keele.ac.uk/researchsupport/researchethics/

Keele University

If you have any queries, please do not hesitate to contact me via the ERP administrator on uso.erps@keele.ac.uk Stating ERP1 in the subject line of the e-mail.

Yours sincerely

HReidy

pp

Dr Jackie Waterfield
Chair – Ethical Review Panel

CC   RI Manager
       Supervisor

Research and Enterprise Services. Keele University, Staffordshire. ST5 5BG. UK
Telephone + 44 (0)1782 734466 Fax: + 44 (0)1782 733740

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Appendix B

Keele University

RESEARCH AND ENTERPRISE SERVICES

24th June 2014

Bushra Bibi
CM1.08
Claus Moser Research Centre

Dear Bushra,

Re: Health literacy and diabetes management: photovoice

Thank you for submitting your revised application for review. I am pleased to inform you that your application has been approved by the Ethics Review Panel. The following documents have been reviewed and approved by the panel as follows:

Document	Version	Date
Summary of Proposal	1	29/04/2014
Information Sheets	1	29/04/2014
Consent Form	1	29/04/2014
Consent Form for the use of quotes and photos	1	29/04/2014
Consent Form for people who may appear in photos	1	29/04/2014
Photovoice Topic Guide	1	29/04/2014
Photovoice Ethics and Safety	2	10/06/2014

If the fieldwork goes beyond the date stated in your application, you must notify the Ethical Review Panel via the ERP administrator at uso.erps@keele.ac.uk stating ERP2 in the subject line of the e-mail. If there are any other amendments to your study you must submit an 'application to amend study' form to the ERP administrator stating ERP2 in the subject line of the e-mail. This form is available via http://www.keele.ac.uk/researchsupport/researchethics/

If you have any queries, please do not hesitate to contact me via the ERP administrator on uso.erps@keele.ac.uk stating ERP2 in the subject line of the e-mail.

Yours sincerely

Dr Bernadette Bartlam
Chair – Ethical Review Panel

CC   RI Manager
      Supervisor

Items	On a scale from very easy to very difficult, how easy would you say it is to:	1 very difficult	2 fairly difficult	3 Fairly easy	4 very easy	5 Don't know
1	... find information on treatments of illnesses that concern you?	1	2	3	4	5
2	...find out where to get professional help when you are ill?	1	2	3	4	5
3	... understand what your doctor says to you?	1	2	3	4	5
4	...understand your doctor's or pharmacist's instruction on how to take a prescribed medicine?	1	2	3	4	5
5	...judge when you may need to get a second opinion from another doctor?	1	2	3	4	5
6	...use information the doctor gives you to make decisions about your illness?	1	2	3	4	5
7	...follow instructions from your doctor or pharmacist?	1	2	3	4	5
8	...find information on how to manage mental health problems like stress or depression?	1	2	3	4	5
9	...understand health warnings about behavior such as smoking, low physical activity and drinking too much?	1	2	3	4	5
10	...understands why you need health screenings?	1	2	3	4	5
11	...judge if the information on health risks in the media is reliable?	1	2	3	4	5
12	...decide how you can protect yourself from illness based on information in the media?	1	2	3	4	5
13	...find out about activities that are good for your mental well-being?	1	2	3	4	5
14	...understand advice on health from family members or friends?	1	2	3	4	5
15	...understand information in the media on how to get healthier?	1	2	3	4	5
16	Judge which everyday behavior is related to your health?	1	2	3	4	5

NEWEST VITAL SIGN UK

READ OUT: This show card gives you the kind of information you might find on the back of a container of ice cream that you just bought at the supermarket. I need to you look at this show card, and then I'm going to ask you to answer some questions. Please have a good read of the information. Let me know when you are finished and we'll move on to the questions.

SHOW CARD:

Product Description: Ice cream

Serving size: 100ml

Serving per container: 4

NUTRITIONAL INFORMATION	
TYPICAL VALUE	Per 100ml
Energy	1050 KJ
	205 kcal (calories)
Protein	**4 g**
Carbohydrate	**30 g**
Of which sugars	23 g
Fat	**13 g**
Of which saturates	9 g
Of which monounsaturates	0 g
Of which polyunsaturates	3 g
Of which trans fats	1 g
Fiber	**0 g**
Sodium	**0.05 g**

Ingredients: Cream, Skimmed milk, Sugar, Whole Egg, Stabilizers (Guar Gum), Peanut Oil, Vanilla Extract (0.05%).

Test Questions:

1 How many calories (kcal) will you eat if you eat the whole container?

PLEASE READ OUT 'KCAL' AS WELL AS CALORIES, BUT NOT 'KILOCALORIES'.

DO NOT READ OUT ANSWER OPTIONS

    A 1,000 KCAL

    B. 1,000 CALORIES

    C. Any other answer

    D. Don't know

    E. Refused

2 If you are advised to eat no more than 60 grams of carbohydrate for dessert, what is the maximum amount of ice cream you could have?

DO NOT READ OUT ANSWER OPTIONS

    A. Two servings (or anything up to 2 servings)

    B. Half the container (or any amount up to half the container)

    C. 200 ml (or any amount up to 200 ml).

    D. Any other answer

    E. Don't know

    F. Refused

3. Imagine that your doctor advises you to reduce the amount of saturated fat in your diet. You usually have 42 g of saturated fat each day, some of which comes from one serving of ice cream. If you stop eating ice cream, how many grams of saturated fat would you be eating each day?

DO NOT READ OUT ANSWER OPTIONS

    A. 33 g

    B. Any other answer

    C. Don't know

    D. Refused

4 If you usually eat 2500 calories each day, what percentage of your daily Calorie (kcal) intake will you get if you eat one serving of ice cream?

PLEASE READ OUT 'KCAL' AS WELL AS CALORIES, BUT NOT 'KILOCALORIES'

DO NOT READ OUT ANSWER OPTIONS

   A. 1/10 (one tenth)

   B. 10%

   C. Any other answer

   D. Don't know

   E. Refused

     READ OUT: Imagine that you are allergic to the following substances: penicillin, Peanuts, latex gloves, and bee stings.

5 Is it safe for you to eat this ice cream?

DO NOT READ OUT ANSWER OPTIONS

   A. Yes

   B. No

   C. Don't know

   D. Refused

     ASK IF 'NO' AT QNVS5

6. Why not?

DO NOT READ OUT ANSWER OPTIONS

   A. Because it contains peanut oil/peanuts/nuts

   B. Because you might have an allergic reaction ASK QNVS7 BELOW

   C. Any other answer

   D. Don't know

   E. Refused

     ASK IF CODE B AT QNVS6:

7. Why would you have an allergic reaction?

DO NOT READ OUT ANSWER OPTIONS

   A. Because it contains peanut oil/peanuts/nuts

   B. Any other answer

   C. Don't know

   D. Refused

Appendix E

Items	Read the statements and tick the best appropriate to you:	Not at all true 1	Hardly true 2	Moderately true 3	Exactly true 4
1	I can always manage to solve difficult problems if I try hard enough.	1	2	3	4
2	If someone opposes me, I can find the means and ways to get what I want.	1	2	3	4
3	It is easy for me to stick to my aims and accomplish my goals.	1	2	3	4
4	I am confident that I could deal efficiently with unexpected events.	1	2	3	4
5	Thanks to my resourcefulness, I know how to handle unforeseen situations.	1	2	3	4
6	I can solve most problems if I invest the necessary effort.	1	2	3	4
7	I can remain calm when facing difficulties because I can rely on my coping abilities.	1	2	3	4
8	When I am confronted with a problem, I can usually find several solutions.	1	2	3	4
9	If I am in trouble, I can usually think of a solution.	1	2	3	4
10	I can usually handle whatever comes my way.	1	2	3	4

Items	In general, I believe that I:	Strongly disagree 1	Somewhat disagree 2	Neutral 3	Somewhat agree 4	Strongly agree 5
1	….know part(s) of taking care of my diabetes that I am **dissatisfied** with.	1	2	3	4	5
2	….am able to turn my diabetes goals into a workable plan.	1	2	3	4	5
3	….can try out different ways of overcoming barriers to my diabetes goals.	1	2	3	4	5
4	…can find ways to feel better about **having** diabetes.	1	2	3	4	5
5	…how the **positive** ways I cope with diabetes-related stress.	1	2	3	4	5
6	…can ask for support for having and caring for my diabetes when I need it.	1	2	3	4	5
7	…know what helps me stay motivated to care for my diabetes.	1	2	3	4	5
8	…know enough about myself as a person to make diabetes care choices that are right for me.	1	2	3	4	5

Appendix G

ADDQoL

This questionnaire asks about your quality of life – in other words how good or bad you feel your life to be.

Please put an "X" in the box that best indicates your response for each item.

What we would like to know is how you feel about your life now.

I) In general, my present quality of life is:

☐	☐	☐	☐	☐	☐	☐
excellent	very good	good	neither good nor bad	bad	very bad	extremely bad

Now we would like to know how your quality of life is affected by your diabetes, its management and any complications you may have.

II) If I did *not* have diabetes, my quality of life would be:

☐	☐	☐	☐	☐
very much better	much better	a little better	the same	worse

Please respond to the more specific statements on the following pages. For each aspect of life described, you will find two parts:

For Part (a):   put an "X" in one box to show how diabetes affects this aspect of your life;

For Part (b):   put an "X" in one box to show how important this aspect of your life is to your quality of life.

1 (a) If I did _not_ have diabetes, I would enjoy my leisure activities:

☐	☐	☐	☐	☐
very much more	much more	a little more	the same	less

(b) My leisure activities are:

☐	☐	☐	☐
very important	important	somewhat important	not at all important

2 Are you currently working, looking for work or would you like to work?

Yes ☐ If _yes_, complete (a) and (b).

No ☐ If _no_, go straight to 3a.

(a) If I did _not_ have diabetes, my working life would be:

☐	☐	☐	☐
very much better	much better	a little better	the same	worse

(b) For me, having a working life is:

☐	☐	☐	☐
very important	important	somewhat important	not at all important

3 (a) If I did _not_ have diabetes, local or long distance journeys would be:

☐	☐	☐	☐	☐
very much easier	much easier	a little easier	the same	more difficult

(b) For me, local or long distance journeys are:

☐	☐	☐	☐
very important	important	somewhat important	not at all important

4	Do you ever go on holiday or want to go on holiday?

Yes ☐ If *yes*, complete (a) and (b).

No ☐ If *no*, go straight to 5a.

(a)	If I did *not* have diabetes, my holidays would be:

☐	☐	☐	☐	☐
very much better	much better	a little better	the same	worse

(b)	For me, holidays are:

☐	☐	☐	☐
very important	important	somewhat important	not at all important

5 (a)	If I did *not* have diabetes, physically I could do:

☐	☐	☐	☐	☐
very much more	much more	a little more	the same	less

(b)	For me, how much I can do physically is:

☐	☐	☐	☐
very important	important	somewhat important	not at all important

6	Do you have any family / relatives?

Yes ☐ If *yes*, complete (a) and (b).

No ☐ If *no*, go straight to 7a.

(a)	If I did *not* have diabetes, my family life would be

☐	☐	☐	☐	☐
very much better	much better	a little better	the same	worse

(b)	My family life is:

☐	☐	☐	☐
very important	important	somewhat important	not at all important

7 (a)	If I did *not* have diabetes, my friendships and social life would be:

☐	☐	☐	☐	☐
very much better	much better	a little better	the same	worse

(b)	My friendships and social life are:

☐	☐	☐	☐
very important	important	somewhat important	not at all important

8	Do you have or would you like to have a close personal relationship (e.g. husband / wife, partner)?
	Yes ☐ If *yes*, complete (a) and (b).
	No ☐ If *no*, go straight to **9**.

(a)	If I did *not* have diabetes, my closest personal relationship would be:

☐ very much better ☐ much better ☐ a little better ☐ the same ☐ worse

(b)	For me, having a close personal relationship is:

☐ very important ☐ important ☐ somewhat important ☐ not at all important

9	Do you have or would you like to have a sex life?
	Yes ☐ If *yes*, complete (a) and (b).
	No ☐ If *no*, go straight to **10a**.

(a)	If I did *not* have diabetes, my sex life would be:

☐ very much better ☐ much better ☐ a little better ☐ the same ☐ worse

(b)	For me, having a sex life is:

☐ very important ☐ important ☐ somewhat important ☐ not at all important

10 (a)	If I did *not* have diabetes, my physical appearance would be:

☐ very much better ☐ much better ☐ a little better ☐ the same ☐ worse

(b)	My physical appearance is:

☐ very important ☐ important ☐ somewhat important ☐ not at all important

11 (a)	If I did *not* have diabetes, my self-confidence would be:

☐ very much better ☐ much better ☐ a little better ☐ the same ☐ worse

(b)	My self-confidence is:

☐ very important ☐ important ☐ somewhat important ☐ not at all important

12 (a)	If I did *not* have diabetes, my motivation would be:				
	☐	☐	☐	☐	☐
	very much better	much better	a little better	the same	worse
(b)	My motivation is:				
	☐	☐	☐	☐
	very important	important	somewhat important	not at all important

13 (a)	If I did *not* have diabetes, the way people in general react to me would be:				
	☐	☐	☐	☐	☑
	very much better	much better	a little better	the same	worse
(b)	The way people in general react to me is:				
	☐	☐	☐	☐
	very important	important	somewhat important	not at all important

14 (a)	If I did *not* have diabetes, my feelings about the future (e.g. worries, hopes) would be:				
	☐	☐	☐	☐	☐
	very much better	much better	a little better	the same	worse
(b)	My feelings about the future are:				
	☐	☐	☐	☐
	very important	important	somewhat important	not at all important

15 (a)	If I did *not* have diabetes, my financial situation would be:				
	☐	☐	☐	☐	☐
	very much better	much better	a little better	the same	worse
(b)	My financial situation is:				
	☐	☐	☐	☐
	very important	important	somewhat important	not at all important

16 (a)	If I did *not* have diabetes, my living conditions would be:				
	☐	☐	☐	☐	☐
	very much better	much better	a little better	the same	worse
(b)	My living conditions are:				
	☐	☐	☐	☐
	very important	important	somewhat important	not at all important

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17 (a)	If I did *not* have diabetes, I would have to depend on others when I do not want to:

☐ very much less   ☐ much less   ☐ a little less   ☐ the same   ☐ more

(b) For me, not having to depend on others is:

☐ very important   ☐ important   ☐ somewhat important   ☐ not at all important

---

18 (a) If I did *not* have diabetes, my freedom to eat as I wish would be:

☐ very much greater   ☐ much greater   ☐ a little greater   ☐ the same   ☐ less

(b) My freedom to eat as I wish is:

☐ very important   ☐ important   ☐ somewhat important   ☐ not at all important

---

19 (a) If I did *not* have diabetes, my freedom to drink as I wish (e.g. fruit juice, alcohol, sweetened hot and cold drinks) would be:

☐ very much greater   ☐ much greater   ☐ a little greater   ☐ the same   ☐ less

(b) My freedom to drink as I wish is:

☐ very important   ☐ important   ☐ somewhat important   ☐ not at all important

---

If there are any other ways in which diabetes, its management and any complications affect your quality of life, please say what they are below:

Thank you for completing this questionnaire.

Appendix H

Demographics and lifestyle

Note: There are no right or wrong answers, choose the answer that suits you.

1. Are you a male or female	Male 1	Female 2

2. How old are you	Years

3 How is your health in general?				
Very good	Good	Fair	Bad	Very bad
1	2	3	4	5

4 Do you have any:	Yes	No
…close relatives whom you speak to or see regularly?	1	2
….close friends whom you speak to or see regularly?	1	2

5 In your job how many hours a week (including paid or unpaid overtime) do you usually work?				
15 hours or less	16-30	31-48	49 or more	Never worked
1	2	3	4	5

6 Do you have any qualification form UK or abroad?	
Yes	1
No	2

7 Which of these qualifications do you have? Please circle all that apply to you:	
A	1-4 O levels/CSEs/ GCSEs (any grade), Entry level, Foundation Diploma
B	NVQ Level 1, Foundation GNVQ, Basic skills

C	5+ O Level (Passes)/ CSEs (grade 1)/ GCSEs (grade A*- C), School Certificate, 1 A level/ 2-3 AS levels/ VCEs, Higher Diploma
D	NVQ Level 2, Intermediate GNVQ, City and Guilds Craft, ONC, OND, BTEC National, RSA Advanced Diploma
E	Apprenticeship
F	2 + A level /VCEs, 4 + AS levels, Higher School Certificate, Progression/ Advanced Diploma
G	NVQ level 3, Advanced GNVQ, City and Guilds Advanced Craft, ONC, OND, BTEC National, RSA Advanced Diploma
H	Degree (for example BA, BSc), Higher degree (for example MA, PhD, PGCE)
I	NVQ LEVEL 4-5, HNC, HND, RSA Higher Diploma, BTC Higher Level
J	Professional Qualifications (for example Teaching, Nursing, Accountancy)
K	Other vocational work related qualifications
L	Foreign qualification
M	No qualification

8   Does your household own or rent your accommodation?

Owns outright	1	Go to the Question 10	Part owns and part rents (shared ownership)	4
Owns with a mortgage or loan	2		Rents (with or without housing benefits)	5
Lives here rent free	3			

9   Who is your landlord?

Housing association, housing co-operative, charitable trust, registered social landlord	1	Employer of a household member	4
Council (local Authority)	2	Relative or friend of a household member	5
Private landlord or letting agency	3	Other	6

10   Looking at either the yearly, monthly or weekly amount, just tick the number which describes the total income for you and your partner/husband/wife (if you have one)?

Yearly	Monthly	Weekly	
0- 4,999	0-417	0-96	1
5,000- 9,999	418-833	97-192	2
10,000- 19,999	834-1,667	193- 385	3
20,000-24,999	1,668- 2, 083	386-479	4
25,000-29,999	2, 084- 2, 499	480-575	5
30,000-34,999	2,500- 2, 915	576-672	6
35,000-or more	2, 916- or more	673- or more	7
Don't know			8
Prefer not to say			9

11 What is your ethnic group?	
Indian	1
Bangladeshi	2
Pakistani	3
Others	4

12   Overall, do you feel that you have a……

Very healthy lifestyle	Fairly Healthy lifestyle	Neither a healthy nor an unhealthy lifestyle	Fairly unhealthy lifestyle	Very unhealthy lifestyle
1	2	3	4	5

13   Generally speaking, do you think that you have a healthy diet?

Yes	No	Don't know what a healthy diet is	Don't know if I have a healthy diet is
1	2	3	4

14   Which of the following best describes you?

I currently smoke	I used to smoke	I have tried cigarettes just once or twice	I have never smoked
1	2	3	4

15   How often do you have a drink containing alcohol?

Everyday	4-6 days a week	1-3 days a week	1-3 days a month	Less than once a month	Never
1	2	3	4	5	6

16   a. In the past week, how many days have you done a total of 30 minutes or more of physical activity, which was enough to raise your breathing rate.

1	2	3	4	5	6	7

b. If four days or less, have you done at least 2 ½ hours (150 minutes) of physical activity over the course of the last week?

Yes	No
1	2

KEELE UNIVERSITY RESEARCH

WE NEED YOUR HELP

ARE YOU:

- 18 years old or over
- South Asian (Indian, Pakistani, Bangladeshi)

We need 20 minutes of your time to complete a simple questionnaire on health. The interview will take place at a time and location of the participant's convenience. This is part of a PhD project on health literacy among South Asians in the UK.

For more information, contact:

Bushra Bibi

Text or call: 07944 502595

Email: b.bibi@keele.ac.uk

Poster for General Participants
Version No: 2
Date: 12 July 2013

Keele University

KEELE UNIVERSITY RESEARCH
WE NEED YOUR HELP

ARE YOU:

- 18 years old or over
- South Asian (Indian, Pakistani, Bangladeshi)
- Have diabetes

We need 30 minutes of your time to complete a simple questionnaire on health. Interview will take place at a time and location of the participant's convenience. This is part of a PhD project on health literacy among South Asians in the UK.

For more information, contact:

Bushra Bibi
Text or call: 07944 502595
Email: b.bibi@keele.ac.uk

Health literacy research at Keele University
Bushra Bibi – 07944 502595
email: b.bibi@keele.ac.uk

Poster for Participants with diabetes
Version No: 2
Date: 12 July 2013

Appendix K

Information Sheet
Health Literacy among South Asians in the UK

You are invited to take part in this research. It is being carried out by Bushra Bibi from Keele University.

Before you decide, it is important that you understand why we are doing this. You can ask questions or ask for more information.

What is this study for? My research is about health literacy. I would like to know the level of health literacy among South Asians living in the U.K.

What is health literacy? People have skills. Health literacy is the set of skills that help people to find, understand, and use health information and services.

Why have I been chosen: I need 200 South Asians in this study. You are chosen because you have a South Asian family background.

Do I have to take part? This is up to you. If you take part, you can also change your mind and leave anytime. You don't need to give a reason.

What will happen if I take part? If you decide to participate, I will ask you to sign two consent forms----one for you and one for my records. After this I will ask you some questions about:

- Your background (for example, your age, gender etc.)
- How you feel about your health
- How you feel about yourself
- Your health literacy level

There will be 49 questions in total. There are no right or wrong answers. After that I will show you an ice cream label. I will ask you 7 questions about it. You can use the label to look for the answers.

Page 1 of 4

Version No: 2
Date: 12 July 2013
1 for participant, 1 for researcher (General Participants)

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Keele
University

Interview will take place at a time and location of the participant's convenience. It will take 15-20 minutes to answer all of the questions.

What are the benefits (if any) of taking part?

This research will help you to think about health literacy. It will be helpful for me to understand the health literacy among South Asians and if there are problems, how it can be improved.

What are the risks (if any) of taking part?

Some of questions may be related to your health. You can tell the researcher if you feel uncomfortable about a question. You don't have to answer everything. You can also ask the researcher to stop if you need a break. You may also leave anytime. You don't need to give a reason why.

How will information about me be used?

We will use a participant number for your response sheet. This means that your name will not be recorded or linked with your responses.

The results will be written as part of my research. I may write articles about it. I may also give talks and presentations about it. I will not use any real names. I will also leave out anything that may identify you. You can also ask for a copy of the report if you wish.

Who will have access to information about me?

Only I and the research supervisors will have access to the information about you. We will keep the questionnaires and consent forms in a lockable filing cabinet at Keele University. We will keep the forms for 10 years and will be destroyed after that.

Who is funding this project?

This is a self-funded PhD project at Keele University.

What if there is a problem?

You may contact Bushra Bibi on b.bibi@keele.ac.uk
Tel (+44) 01782 7 33276

Claus Moser Research Centre 1.04
University of Keele
ST5 5BG

If you do not wish to contact the researcher, you may contact Dr Emee Vida
Estacio (Lead Supervisor) on e.v.g.estacio@keele.ac.uk
Tel (+44) 01782 7 33332
Dorothy Hodgkin Building 1.76
University of Keele
ST5 5BG

If you remain unhappy about the research and wish to raise a complaint, you
can contact
Nicola Leighton
Research Governance Officer
Research and Enterprise Services, Dorothy Hodgkin Building
Keele University, ST5
E-mail: n.leighton@uso.keele.ac.uk
Tel: 01782 733306

Where can I get more information about improving my skills?
You may contact Adult and Community Learning
Tel (during the hours 9-5 Mon-Fri): 01782 234775
Email: adult.learning@stoke.gov.uk
Facebook: www.facebook.com/AdultLearningStoke

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CONSENT FORM

Keele University

Title of Project: Health Literacy among South Asians in the UK

Name and contact details of Principal Investigator:
Bushra Bibi, School of Psychology, Keele University ST5 5BG
Tel (+44) 01782 7 33276 Email b.bibi@keele.ac.uk

Please tick box if you agree with the statement

I confirm that I understand the information about the above study and have had the opportunity to ask questions. □

I understand that my participation is voluntary and that I am free to withdraw at any time. □

I agree to take part in this study. □

I understand that data collected about me during this study will be anonymised before it is submitted for publication. □

I agree to allow the dataset collected to be used for future research projects □

I agree to be contacted about possible participation in future research projects. □

_____   _____   _____
Name of participant   Date   Signature

_____   _____   _____
Researcher   Date   Signature

Page 4 of 4

Version No: 2
Date: 12 July 2013
1 for participant, 1 for researcher (General Participants)

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Appendix L

Keele University

Information Sheet
Health Literacy and diabetes management

You are invited to take part in this research. It is being carried out by Bushra Bibi from Keele University.

Before you decide, it is important that you understand why we are doing this. You can ask questions or ask for more information.

What is this study for? We want to know how you deal with diabetes. We also want to know if health literacy influences how you manage diabetes.

What is health literacy? People have skills. Health literacy is the set of skills that help people to find, understand, and use health information and services.

Why have I been chosen: I need 150 South Asians who have diabetes. I chose South Asians because diabetes is common for this group. You are chosen because you have a South Asian background and have diabetes.

Do I have to take part? This is up to you. If you take part, you can also change your mind and leave anytime. You don't need to give a reason.

What will happen if I take part? I will ask you to sign two consent forms -- one for you and one for my records. After this I will ask you some questions about:

- Your background (for example, your age, gender etc.)
- How you feel about your health
- How you feel about yourself
- Your health Literacy
- How you manage your diabetes
- Your life after getting diabetes

There will be 66 questions in total. There are no right or wrong answers.

After that I will show you an ice cream label. I will ask you 7 questions about it. You can use the label to look for the answers.

Interview will take place at a time and location of participant's convenience. It will take 25-30 minutes to answer all of the questions.

Page 1 of 4

![Keele University]

What are the benefits (if any) of taking part:

This research can help you to think about your health and how you are managing diabetes. We can use the information to let others know about diabetes management.

What are the risks (if any) of taking part?

Some questions will be about diabetes. You can tell the researcher if you feel uncomfortable about a question. You don't have to answer everything. You can also ask the researcher to stop if you need a break. You may also leave anytime. You don't need to give a reason why.

How will information about me be used?

We will use a participant number for your response sheet. This means that your name will not be recorded or linked with your responses.

The results will be written as part of my research. I may write articles about it. I may also give talks and presentations about it. I will not use any real names. I will also leave out anything that may identify you. You can also ask for a copy of the report if you wish.

Who will have access to information about me?

Only I and the research supervisors will have access to the information about you. We will keep the questionnaires and consent forms in a lockable filing cabinet at Keele University. We will keep the forms for 10 years and will be destroyed after that.

Who is funding this project?

This is a self-funded PhD project at Keele University.

Keele University

What if there is a problem?

You may contact Bushra Bibi on b.bibi@keele.ac.uk
Tel (+44) 01782 7 33276
Claus Moser Research Centre 1.04
University of Keele
ST5 5BG

If you do not wish to contact the researcher, you may contact Dr Emee Vida Estacio (Lead Supervisor) on e.v.g.estacio@keele.ac.uk
Tel (+44) 01782 7 33332
Dorothy Hodgkin Building 1.76
University of Keele
ST5 5BG

If you remain unhappy about the research and wish to raise a complaint, you can contact
Nicola Leighton
Research Governance Officer
Research and Enterprise Services, Dorothy Hodgkin Building
Keele university, ST5 5BG
E-mail: n.leighton@uso.keele.ac.uk
Tel: 01782 733306

Where can I find more information about diabetes?
You may contact the Diabetes UK Careline at 0845 120 2960
Monday–Friday, 9am–5pm
Email: careline@diabetes.org.uk
Website: http://www.diabetes.org.uk

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Keele University

CONSENT FORM

Title of Project: Health Literacy and diabetes management

Name and contact details of Principal Investigator:
Bushra Bibi, School of Psychology, Keele University ST5 5BG
Tel (+44) 01782 7 33276 Email b.bibi@keele.ac.uk

Please tick box if you agree with the statement

I confirm that I understand the information about the above
study and have had the opportunity to ask questions. ☐

I understand that my participation is voluntary and that I
am free to withdraw at any time. ☐

I agree to take part in this study. ☐

I understand that data collected about me during this study
will be anonymised before it is submitted for publication. ☐

I agree to allow the dataset collected to be used for future
research projects ☐

I agree to be contacted about possible participation in
future research projects. ☐

_____ _____ _____
Name of participant   Date   Signature

_____ _____ _____
Researcher   Date   Signature

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Appendix M

Instruction sheet for collecting questionnaire data

- Read this statement to the participants:

This study is about health literacy and diabetes management. I would like to know the level of health literacy and diabetes management amongst South Asians living in UK. I will ask you 66 questions (Background information, health, quality of life, diabetes management and health literacy). It will take approximately 25-30 minutes to answer all the questions.

- Do you have any question?

[Answers will be given to the questions asked by the participants]

- Procedure:

It will be told to the participants, this is not a test, and there is no right or wrong answers. This is for research purposes so answer it honestly. Read the questionnaire to the participants so that who have limited literacy they do no intimidate about it. Answers will be recorded to the questionnaire sheet.

Appendix N

Keele University

INFORMATION FOR PARTICIPANTS

I would like to invite you to help me in my research. I want to know how people deal with diabetes. I am doing this so we can better support people like you.

Please read this information sheet before you decide. If anything is unclear, you can contact me at **07944 502595**. You can also email us at b.bibi@keele.ac.uk.

You may discuss this information sheet with friends or relatives if you wish.

==

Why have I been invited?

You are someone who has diabetes and have South Asian family background. I am looking for South Asian men and women to take part in this project.

Do I have to take part?

You are free to decide if you want to take part or not. It's your choice.

What will happen if I decide to take part?

You will take pictures about your experiences of diabetes for two weeks. We will give you a camera, but if you like, you can use your own. We will print the photos for you. You then choose which photos you would like to share and which ones you would like to keep to yourself. You may talk about your photos and share your stories with us. We will invite other participants to share their photos too. We will ask everyone's permission to record the discussions.

What are the benefits of taking part?

Taking part will help me to understand your needs of diabetes management so that we can support you better.

What are the risks of taking part?

There are no risks involved in taking part in this project.

What if I say 'yes' and then decide later that I don't want to take part?

You are free to leave any time. You don't need to explain why.

What will you do with the information from this research?

I will write a report as part of my PhD at Keele University. I will also write articles about the project. I will not use any real names and will leave out anything that may identify you. I will also give you a copy of the report if you wish.

I will also organise a photo exhibition to show the best photos from this project. You can tell me if you don't want your photos to be shown to others. I will let you know when and where the exhibition will take place. I hope that you'll be able come to the exhibition if you can.

What will happen to the information collected after the research?

Everything will be kept strictly confidential. The information will be kept at Keele University for ten years. It will be destroyed after that.

How can I let you know that I would like to take part?
You can call me or send me a text message on this number: 07944502595 or email at b.bibi@keele.ac.uk.

Who should I contact if I have any questions or concerns?

Bushra Bibi on b.bibi@keele.ac.uk
Tel (+44) 01782 7 33883
Claus Moser Research Centre 1.08
University of Keele
ST5 5BG
If you do not wish to contact the researcher, you may contact Dr Emee Vida Estacio (Lead Supervisor) on e.v.g.estacio@keele.ac.uk
Tel (+44) 01782 7 33332
Dorothy Hodgkin Building 1.76
University of Keele
ST5 5BG

If you remain unhappy and want to make a complaint, you may contact:

Nicola Leighton
Keele University Research Governance Officer
Research and Enterprise Services, Keele University, ST5 5BG
Email n.leighton@uso.keele.ac.uk
Tel. 01782 733306

Where can I find more information about diabetes?
You may contact the Diabetes UK Careline at 0845 120 2960
Monday–Friday, 9am–5pm
Email: careline@diabetes.org.uk
Website: http://www.diabetes.org.uk

Appendix O

CONSENT FORM

Study title: Health literacy and diabetes management: Photovoice
Name of Principal Investigator: Bushra Bibi

Please tick box

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time. ☐

3. I agree to take part in this study. ☐

4. I understand that data collected about me during this study will be anonymised before it is submitted for publication. ☐

5. I agree to the discussion being audio taped. ☐

6. I agree to allow the data collected to be used for future research projects. ☐

7. I agree to be contacted about possible participation in future research projects. ☐

_____   _____   _____
Name of participant   Date   Signature

_____   _____   _____
Researcher   Date   Signature

Keele University

CONSENT FORM: USE OF QUOTES AND PHOTOGRAPHS

Study title: Health literacy and diabetes: Photovoice
Name of Principal Investigator: Bushra Bibi

Please tick applicable:

USE OF QUOTES

☐ I agree for any quotes to be used.

☐ I do NOT want any quotes to be used.

☐ I want to see any proposed quotes before making a decision.

USE OF PHOTOGRPAHS FOR THE ANALYSIS

☐ I have selected photographs to be included in this study and I am happy for the researchers to use these for analysis.

☐ I do NOT want my photographs to be included in the analysis.

USE OF PHOTOGRAPHS FOR THE EXHIBITION

☐ I have selected photographs to be included in the exhibition and I am happy for the researchers to use these for this purpose.

☐ I do NOT want my photographs to be included in the exhibition.

_____	_____	_____
Name of participant	Date	Signature
_____	_____	_____
Researcher	Date	Signature

Appendix P

Keele University

Health literacy and diabetes management: Photovoice Project

Consent Form for People Who May Appear in Photographs

Introduction

This photovoice project is part of the PhD research at Keele University. The goal of this project is to explore issues surrounding the diabetes management of South Asians in the UK.

What is Photovoice?

Photovoice provides a way for people to explore and communicate their perceptions and experiences related to diabetes management. Participants will take pictures about diabetes management. The pictures will be discussed with other participants, who will explain why they took the pictures and what they mean. We will also organise an exhibition at the end of the project.

What is involved?

The photographer may take pictures that contain images of you. Your name or any other identifying information will not be known or listed with the photographs. It is good to remember that there is always the chance someone may recognise you in the photographs. Your willingness to be photographed is voluntary and you may refuse.

What happens to the photograph?

Photographs become the property of Keele University and may be used in public exhibits, presentations, publications and/or other purposes.

By signing this consent form, I agree to voluntary have my photograph taken. I understand and agree that unless otherwise notified in writing, Keele University assumes that permission is granted to use the photograph (s) for public exhibits, presentations, publications and/or others purposes.

Thanks for your time and help!

Name:_____   Date: _____

Signature: _____

Any Questions? Contact Bushra Bibi, Claus Moser Research Centre, 1.08, Keele University ST5 5BG, Staffordshire OR Email: b.bibi@Keele.ac.uk

Keele University

Photovoice Topic Guide

What will I take photo of?

You will be asked to take photographs related to diabetes management. Here are some of the themes you can consider in taking photographs:

(1) Situation or activities relating to how you manage diabetes

(2) Your experience related to healthcare system and how you use it to manage diabetes

(3) What things you feel that needs to be changed in health system to help you to manage diabetes better

What will I be doing with my photographs?

I)   Group discussion or one to one

When the photographs have been printed and have selected those that you wish to share, you will be asked to talk about them in more detail.

Questions for discussion might be:

1). Tell me something about these photos

2). What's the story behind this photo?

3). Why have been taken this photo?

II)   Photovoie exhibition

This will take place at the ( ), after the project has finished. Anyone is free to take part. There will be:

1. Your photos on display

2. People invited such as people with diabetes, health professionals, community organizations, policy makers and other people related to work in health related area.

3. There will be a chance for you to talk about your photos to others

Appendix R

Photovoice Ethics and Safety

Ground rules and respect for others

You can be as fun, creative and adventurous as you like with your photography!

Photos can be as factual or as symbolic as you wish. But it is important that we cover a few basic ground rules:

- Taking a photograph of somebody without his or her permission is a violation of privacy.
- Asking for someone's permission to photograph him/her is not just an important ground rule; it is a good opportunity to tell others about your project.

When to use the photographed persons consent forms:

- *When you take a photograph of another person.* Ask that person first to read and agree to sign the photographed person's consent form.

- *When you take a photograph of another person who is under 18 years old*. Ask their parent/guardian to read and agree to sign the photographed person's consent form.

This may all sound very formal but it is necessary to show others that we have respected people's privacy. If someone doesn't want their photograph taken, don't worry about it! There will be other opportunities to take other photos for this project.

Personal safety:

- Always use your judgment -- don't put yourself in a risky situation.

- Always ask before taking a photo of someone or someone's property.

- Take a friend or let someone know if you are going somewhere unfamiliar.

- Don't do anything dangerous or risky that you wouldn't usually do.

- Be aware of your surroundings.

- If you do happen to be confronted by somebody aggressively, think safety first! If asked, hand over your camera and tell someone.

If you have any other questions or concerns, Contact Bushra Bibi on b.bib@keele.ac.uk

Tel (+44) 01782 7 33883, Claus Moser Research Centre 1.08 University of Keele, ST5 5BG

Appendix S

Initial notes patterns	Lines (names)	Codes	Sub-themes	Provisional names	Final theme
Popularity of sweets Plenty of oil and species Deep fried food Use of sweet as a one reason for developing diabetes Female responsible for cooking Cooking in large portions Quantity of food as social status Peer pressure for eating on social gatherings Less healthy food options on social gatherings Don't care about meal times Need to reflect on eating habits Popularity of fast food in young generation Eating late night Eating in large portions to avoid break during work Work demands as barrier in eating healthy Lack of readability of product labels Different measures for food intake Karaila vegetable as treating element to diabetes Okara as part of treatment to diabetes Neem tree leaves as part of treating diabetes Grilled food Changed cooking methods I eat fruits during late night Need to raise awareness amongst females	1140-1149, 1104-1115, 1297-1321 (Wajeeha) 227-236 (Nasib) 1974-1978, 2292-2309 (Parveen) 1979-1991, 1999-2006(Ibrar) 2507-2511, 2964-2980 2507-2511, 2759-2767(Saleem) 576-587, 576-587 (Fatima) 1332-1347, 1392-1396(Saeed) 3559-3567, 3414-3416(Umer) 2873-2888, 2863-2872(Zafar) 4032-4041(Tayyab)	South Asian traditional diet as a risk for diabetes Cultural norms and traditions Eating habits and behaviours Work life and healthy eating Food literacy Food as a treating element to diabetes Food patterns after diabetes	Lifestyle	Individual-context	Illustration of self-management in day to day life

'Should do exercise' Gardening as a hobby-inside activities of home Work-based activity as substitute to work Positive experiences of doing exercise after diabetes we come less towards exercise Women prefer to stay inside Leisure time activities Sedentary lifestyle We do less exercise Less physical activity in children Group activity to increase physical activity level I feel guilty- work and life is not balanced Weather conditions of not doing physical activity Socioeconomic factor as barrier in exercise Backache as reason for not doing exercise Loss of motivation to keep continue physical activity	4099-4103, 4103-4110, 4184-4199 (Tayyab) 2102-2109, 2188-2199 (Ibrar) 87-96(Fatima) 2211-2213(Parveen) 1230-1248, 1498-1414, 1208-1220(Saeed) 18-24(Naseeb) 1058-1068(Wajeeha) 2820-2836(Saleem) 4119-4125(Umer) 2851-2861(Zafar)	Knowledge and action Cultural norms and traditions Perceived barriers to physical activity			

Medicine is important Diabetes management with balanced diet at start Side-effects of medications Co-morbidity of diseases Balance is out of control Picture of diabetes complications on medicine pack aging Use of medicine from hakim Spiritual ways of handling 'be patient' Not regular in checking blood glucose It is important Regular monitoring as a reassurance Subjective feeling to tell blood glucose level Healthcare professionals responsible for blood glucose monitoring Family support in checking blood glucose level	97-98, 109-120(Fatima) 40-46, 339-345(Naseeb) 2139-2143, 2114-2119(Ibrar) 2120-2138, 2235-2243(Parveen) 3196-3212, 3185-3189, 3912-3920(Umer) 2639-2652(Zafar) 3158-3176, 2539-2553(Saleem) 4055-4063(Tayyab) 52-53(Nasib)	Medicine intake and adherence Alternative cultural medications Perception and action in blood glucose level monitoring External support	Clinical measures of management	
Lack of reading product label/information leaflets Less calories calculation English language as barrier in accessing information Information in native language can improve utility of written information Less motivation for self-study Self-study to escape embarrassment Support from family for getting information Children read the information leaflets Use of internet for searching information Less participation in research You are in charge of your health	336-339(Naseeb) 1694-1702, 1529-1544(Saeed) 4200-4216(Tayyab) 2250-2527, 2530-2538, 2550-2565(Saleem) 2318-2325(Ibrar) 1458-1471(Wajeeha)	Personal and family resources Civic health literacy	Personal skills and capacities	

			Access and utility of healthcare services	Healthcare-context	NHS access and utility in diabetes management
Location of primary care centres Difficulty in booking appointment Time pressure during appointment Less use of written material English language as barrier in accessing services/information Cultural clash in psychological services Less awareness about different healthcare services Less comprehension about complexity of the healthcare system Doctor as main source of information Help on demand Satisfied with the services Utilisation of diabetes specific services Exemption certificate No utility of educational course to improve self-management Regular reviews for diabetes	2369-2378(Zafar) 1153-1166(Wajeeha) 729-748(Fatima) 3757-3771(Umer) 2007-2010(Parveen) 294-308(Naseeb) 2256-2273(Parveen) 130-136(Naseeb) 2708-2713(Zafar)	Access to health care services Utility of health resources Comprehension of healthcare system Utility of diabetes care services			

			Experience with healthcare professionals		
Stereotyping towards south Asians Discouraging attitude of the healthcare professionals Lack of encouragement restrict sharing problems She does not understand you Healthcare professionals should have knowledge about culture of ethnic communities Needs to have Palin and simple language Consideration of the cultural, language and education background of the patients NHS staff need to have empathic attitude towards people with limited information	698-701, 632-637(Fatima) 2048-2069(Parveen) 1623-1643,1017-1026(Wajeeha) 1752-1783, 1771-1783(Saeed)	Trust towards healthcare professionals Cultural compatibility			
More information in native language Alternative sources of information Use of media to raise awareness Should ask more questions Specific information according to needs Information need to spread within the community Community members needs to work as mentors Use of mosque as platform for raise awareness	704-713, 930-937(Fatima) 999-1010, 1480-1491(Wajeeha) 2042-2047(Ibrar) 1590-1610, 1611-1623, 1428-1437 (Saeed) 2436-2455, 2486-2494(Zafar) 2015-2082(Parveen) 3035-3045(Abid) 2561-2580, 3072-3090(Saleem)	Alternative sources according to need of the community Effective face to face communication Utility of community resources	Expressed needs and recommendations		

Feet hurt I can do less physically Physical effects of diabetes I feel more fragile after diabetes Easily stressed out Struggle to manage daily life demands with diabetes Perception towards diabetes as a disease Complications are not preventable Traveling problems Struggle to have regular intake of medications Lack of balance in life Eating less traditional food items Eating fruits during late night as a snack Material support from family Social support from family Females changed cooking tradition after diabetes Less hours of job after diabetes Effects on work life Nature of job as hindrance to diabetes care Working patterns as negative impact on diabetes Needs organization to manage the job with diabetes	26-38, 501-508,530-535(Naseeb) 3714-3753, 3991-4001(Umer) 2169-2177,2156-2167(Ibrar) 2672-2703(Zafar) 1960-1966(Parveen) 1312-1314(Wajeeha) 2789-2796, 2496-2506, 3057-3071(Saleem) 677-683(Fatima) 3333-3343, 3595-3606, 3610-3619(Umer) 1221-1228(Saeed) 3019-3025(Abid)	Physical effects Psychological effects Perceived lack of control Changed eating habits Family support Work life after diabetes	Quality of life	Quality of Life

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